

**Systems of Care  
Promising Practices in Children's Mental Health  
1998 Series**

**VOLUME II  
PROMISING PRACTICES IN  
FAMILY-PROVIDER COLLABORATION**

**Research and Training Center on Family Support and  
Children's Mental Health  
Portland State University**

**Authors:**

Jennifer S. Simpson, Ph.D.

Nancy Koroloff, Ph.D.

Barbara J. Friesen, Ph.D.

Jennifer Gac, M.S.W.



Child, Adolescent, and Family Branch  
Division of Knowledge Development and Systems Change  
Center for Mental Health Services  
Substance Abuse and Mental Health Services Administration  
U.S. Department of Health and Human Services

**U.S. Department of Health and Human Services**

Donna Shalala

*Secretary*

**Substance Abuse and Mental Health Services Administration**

Nelba Chavez

*Administrator*

**Center for Mental Health Services**

Bernard S. Arons, *Director*

**Division of Knowledge Development and Systems Change**

Michael English, *Director*

**Child, Adolescent, and Family Branch**

Gary De Carolis, *Chief*

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# Table of Contents

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FOREWORD.....	5
ACKNOWLEDGMENTS.....	7
EXECUTIVE SUMMARY .....	9
CHAPTER I: OVERVIEW AND DISCUSSION .....	17
Background to the Role of Families in Systems of Care .....	19
Definition and Components of Family-Provider Collaboration .....	23
Method and Organization .....	29
Promising Practices at Four Child Mental Health Initiative Sites .....	31
Discussion .....	34
Dimensions of Family-Provider Collaboration .....	35
CHAPTER II: PROMISING PRACTICES AT FOUR CHILDREN’S MENTAL HEALTH SITES .....	39
North Carolina PEN-PAL and FACES .....	39
K’e Project, Navajo Nation .....	47
Sonoma-Napa County Comprehensive System of Care, California .....	62
East Baltimore Mental Health Partnership, Maryland .....	73
CHAPTER III: RESOURCES FOR FAMILY-PROVIDER COLLABORATION .....	81
<u>Rural and Native American Sites</u>	
Hawaii Ohana Project and Hawaii Families as Allies .....	81
KanFocus and Parent T.E.A.M.S., Southeast Kansas .....	82
North Dakota Partnership Program and North Dakota Federation of Families .....	88
Dream Catchers Family Advocates, Southern Ohio Consortium for Children .....	91
Vermont Access Project .....	94
Kmihqitahasultipon Program, Indian Township, Maine .....	96
<u>Small City/County Sites</u>	
San Mateo County Health and the Family Partnership Team, California .....	102
Santa Cruz County Children’s Mental Health and the Family Advisory Council, California ..	103
Stark County Family Council, Stark County, Ohio .....	105

Table of Contents, continued

<u>Urban Sites</u>	
Project Heartbeat, San Diego, California .....	107
Families Reaching in Ever New Directions (F.R.I.E.N.D.S), Mott Haven, New York .....	110
South Philadelphia Family Partnership Project .....	112
Wraparound Milwaukee, .....	117
References .....	119
Appendix A: Description of Challenges to Family-Provider Collaboration .....	125
Appendix B: List of Acronyms and Abbreviations .....	129

# Foreword

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It is with great pleasure that we present the first collection of monographs from the *Promising Practices Initiative* of the Comprehensive Community Mental Health Services for Children and Their Families Program. The Comprehensive Community Mental Health Services for Children and Their Families Program is a multi-million dollar grant program that currently supports 41 comprehensive systems of care throughout America, helping to meet the needs of many of the 3.5 to 4 million children with a serious emotional disturbance living in this country. Each one of the seven monographs explores a successful practice in providing effective, coordinated care to children with a serious emotional disturbance and their families.

The 1998 Series marks a turning point in this five-year-old federal effort, which is administered by the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration of the U.S. Department of Health and Human Services. The first generation of five-year grants is about to come to an end, and with that “graduation” comes a responsibility to add to the national knowledge base on how best to support and service the mental health needs of children with serious emotional disturbance. Until the very recent past, these young people have been systematically denied the opportunity to share in the home, community and educational life that their peers often take for granted. Instead, these children have lived lives fraught with separation from family and community, being placed in residential treatment centers or in-patient psychiatric centers, hundreds and even thousands of miles away from their home. For many of these young people, a lack of understanding of their psychopathology, underdeveloped or non-existing community resources, and a sense of frustration of what to do have led to their eventual placement away from home.

The *Promising Practices Initiative* is one small step to ensure that all Americans can have the latest available information about how best to help serve and support these children at home and in their community. Children with serious emotional disturbance utilize many publicly funded systems, including child welfare, juvenile justice, special education, and mental health, and they and their families often face many obstacles to gaining the care they need due to the difficulties and gaps in navigating multiple service systems. Systems of care provide a promising solution for these children and their families by coordinating or integrating the services and supports they need across all of these public service systems.

The information contained within these monographs by and large has been garnered within the original 31 grants of the Comprehensive Community Mental Health Services for Children and Their Families Program. The research was conducted in a manner that mirrored the guiding principles of the systems of care involved so that it was family-driven, community-based, culturally relevant, and inclusive. Methods for information collection included: site visits and focus groups; accessing data gathered by the national program evaluation of all grantees; and numerous interviews of professionals and parents. Family members were included in the research and evaluation processes for all of the monographs. Two of the papers directly address family involvement, and all of the papers dedicate a section to the family's impact on the topic at hand. The research was drawn from the community-based systems of care and much of the research comes from systems of care with *culturally diverse populations*.

The 1998 *Promising Practices* series includes the following volumes:

Volume I - *New Roles for Families in Systems of Care* explores ways in which family members are becoming equal members with service providers and administrators, focusing specifically on two emerging roles: family members as “system of care facilitators” and “family as faculty.”

Volume II - *Promising Practices in Family-Provider Collaboration* examines the fundamental challenges and key aspects of success in building collaboration between families and service providers.

Volume III - *The Role of Education in a System of Care: Effectively Serving Children with Emotional or Behavioral Disorders* explores sites that are overcoming obstacles to educating children with a serious emotional disturbance and establishing successful school-based systems of care.

Volume IV - *Promising Practices in Wraparound* identifies the essential elements of wraparound, provides a meta-analysis of the research previously done on the topic, and examines how three sites are turning wraparound into promising practices in their system of care.

Volume V - *Promising Practices: Training Strategies for Serving Children with Serious Emotional Disturbance and Their Families in a System of Care* examines theories of adult learning, core values, and four key areas (cultural competence, family-professional relationships, systems thinking, and inter-professional education and training), and looks at promising practices that are combining these concepts into a successful sustainable training program.

Volume VI - *Promising Practices: Building Collaboration in Systems of Care* explores the importance of collaboration in a system of care focusing on three specific issues: the foundations of collaboration, strategies for implementing the collaborative process, and the results of collaboration

Volume VII - *In A Compilation of Lessons Learned from the 22 Grantees of the 1997 Comprehensive Community Mental Health Services for Children and Their Families Program*, the grantees themselves share their experiences in five main areas: family involvement/empowerment, cultural competency, systems of care, evaluation, and managed care.

These seven documents are just the beginning of this process. As you read through each paper, you may be left with a sense that some topics you would like to read about are not to be found in this series. We would expect that to happen simply because so many issues need to be addressed. We fully expect this series of documents to become part of the culture of this critical program. If a specific topic isn't here today, look for it tomorrow. In fact, let us know your thoughts on what would be most helpful to you as you go about ensuring that all children have a chance to have their mental health needs met within their home and community.

So, the 1998 *Promising Practices* series is now yours to read, share, discuss, debate, analyze, and utilize. Our hope is that the information contained throughout this Series stretches your thinking and results in your being better able to realize our collective dream that all children, no matter how difficult their disability, can be served in a quality manner within the context of their home and community. COMMUNITIES CAN!

Nelba Chavez, Ph.D.  
Administrator  
Substance Abuse and Mental Health  
Services Administration

Bernard Arons, M.D.  
Director  
Center for Mental Health Services

# Acknowledgments

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# Executive Summary

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## INTRODUCTION

Family-provider collaboration in systems of care is a process that individuals involved in a system engage in to improve services for children and their families. Systems of care are increasingly valuing family-provider collaboration, and are working at policies and practices that support this value. Collaboration among families and providers can result in services that respond to the particular needs of a local community, that are strengthened by the expertise and input of a range of people concerned with children's mental health, and that are more likely to be family-friendly.

Families of children with emotional, mental, or behavioral needs, as well as like-minded professionals, have been advocating for family participation in designing and shaping services in systems of care for approximately 15 years. In the past, families were often blamed for children's problems and rarely valued for their expertise and ability to participate in systems of care. More recently, families are increasingly integral to effective systems of care. Families are being accepted for their knowledge and ideas about how to improve services to their children and how to strengthen the service delivery system. Growing numbers of participants in systems of care are viewing family-provider collaboration as a central component of relevant and respectful delivery of services. This monograph addresses the process and practice of family-provider collaboration. The *Promising Practices in Family-Provider Collaboration* monograph is one of several monographs supported by the Center for Mental Health Services (CMHS), and is part of the Comprehensive Community Mental Health Services for Children and Their Families Program (known also as the Child Mental Health Initiative). This monograph focused on systems of care currently receiving grant assistance from CMHS. These are referred to as Child Mental Health Initiative sites.

Under the leadership of the Child, Adolescent and Family Branch of the Center for Mental Health Services, 44 grants have been awarded to sites across the United States who applied for funds to improve systems of care for children. CMHS has a clear directive to Child Mental Health Initiative sites that they implement family-provider collaboration within their systems of care. This directive provides a unique opportunity for communities to work at collaboration when offering services to children with emotional, behavioral, and mental disorders and their families. As the federal grant guidelines state, successful implementation of systems of care at the Child Mental Health Initiative sites depends on "the full involvement and partnership of families in: (1) the planning, development, implementation, management and evaluation of the local service system; and (2) the care of their children and adolescents" (U.S. Department of Health and Human Services, 1998). While the authors hope this monograph is useful to a range of participants in a wide variety of systems of care, it is particularly intended for communities, both current and future, who are looking for strategies to increase family participation in systems of care and to expand family-provider collaboration. Several questions central to this monograph include:

- What is family-provider collaboration? How does it happen?
- What are the primary challenges to family-provider collaboration?

- How do specific sites approach family-provider collaboration?
- What strategies and practices have sites developed in working toward collaboration?

## **DEVELOPMENT OF THE MONOGRAPH**

In addressing the topic of family-provider collaboration, the authors of this monograph drew heavily on the expertise of families and providers in Child Mental Health Initiative sites. In addition to a literature review, ongoing conversations, telephone interviews, and sites visits were critical to this monograph. All of these components guided the content of the monograph and the format in which we chose to present our findings.

In writing this monograph, a central component of understanding family-provider collaboration was identification of the challenges that participants in systems of care face in achieving collaboration. After identifying a list of two primary and ten secondary challenges, we distributed nomination forms to site directors and family coordinators at approximately 30 Child Mental Health Initiative grant sites. Family members and providers were invited to nominate Child Mental Health Initiative sites (their own and other sites) that had developed or were developing creative strategies and approaches to address the secondary challenges. Below is a brief list of the challenges that are central to our discussion of family-provider collaboration.

### **Challenges to Family-Provider Collaboration**

#### **Primary Challenges**

- (1) A low commitment to and respect for the participation of family members in the system of care; and
- (2) A lack of agreement among family members and providers on how collaboration is defined and practiced within a system of care, and more particularly, agreement on how power is shared.

#### **Secondary Challenges**

- (1) Achieving trust and reducing suspicion
- (2) Incomplete or uneven training in collaboration
- (3) Reaching consensus on vision and goals
- (4) Sustaining new roles and relationships
- (5) Resistance to family participation from other service systems
- (6) Sustainability of the family organization
- (7) Concerns regarding confidentiality
- (8) The existence of tokenism
- (9) Reflecting community norms in system of care
- (10) Imbalance of power related to financial decisions

In the first section, we provide an overview of and background to family-provider collaboration. In addition to addressing the ways in which participants in systems of care have viewed families of children with emotional, behavioral, and mental health needs in the last few decades, we discuss components of family-provider collaboration. The final pages of this section offer conclusions concerning family-provider collaboration generated by conversations with participants in systems of care.

The second section looks closely at the role of families at four different Child Mental Health Initiative sites offering services to children with emotional, behavioral, and mental disorders and their families. Drawing on the experiences of the PEN-PAL and FACES Projects in North Carolina, the K'e Project on the Navajo Nation, the Napa County System of Care and the Sonoma County System of Care in California, and the East Baltimore Mental Health Partnership in Maryland, we identify several processes that directly contribute to family-provider collaboration and family-centered services.

The third section features thirteen profiles. Each of these profiles identifies specific ways in which Child Mental Health Initiative sites are working toward family-centered services. This section describes strategies, practices, and approaches sites are using to work out family-provider collaboration and details the development and implementation of each practice.

## **OBSERVATIONS OF PROMISING PRACTICES**

Through our in-depth conversations with participants in many systems of care, it was inordinately clear that participants in systems of care are finding new ways to work together. As families and professionals continue to assert the value of family participation in children's mental health services, systems of care are increasingly characterized by partnerships with families. Families and providers are finding ways to interact that are respectful and collaborative. Family participation in systems of care changes how services for children with emotional, behavioral, and mental disorders and their families are conceptualized and delivered.

At the same time, family-provider collaboration is never a given. Participants in systems of care have found that meaningful and ongoing movement away from attitudes and actions that blame and devalue families can be difficult to accomplish and sustain. Systems and people change slowly. Frequently, participants within a service system change at different paces and in various rhythms. Delivery of services that used to be straightforward and obvious may seem complicated and ambiguous. Discomfort and tension may seem too often present.

Family-provider collaboration occurs when participants in systems of care are ready to work at change. In addressing four sites in an in-depth manner, and in featuring 13 profiles, we sought to maintain geographic and cultural balance; provide examples of promising practices (and not exemplary or "perfect sites"); and feature Child Mental Health Initiative sites that each offer different and unique insights. The four in-depth descriptions of family-provider collaboration focus on the process each of the sites has worked with to move toward collaboration. A summary follows:

- In Pitt, Edgecombe, and Nash counties, North Carolina, families and providers are particularly aware of the importance of the following to family-provider collaboration:

- local family organizing as a key component in meeting the unique needs of the community, and
- perseverance and a willingness to try a variety of avenues to accomplish a particular objective.

Site directors and family coordinators emphasized the benefit of local family organizing to the delivery of services. Strong ties to local families and organizations support an awareness of strengths, needs, and social norms within particular communities.

- On the Navajo Nation in New Mexico, Arizona, and Utah, staff at the K'e Project work in a context where Navajo philosophy and culture are more predominant than the assumptions and beliefs embedded in non-Navajo approaches. The K'e Project is a profound example of one system of care that values family-centered services. In particular, Navajo traditional approaches to healing:
  - understand the family as central to a child's health and well-being;
  - view the child's mental, behavioral, and emotional health as intricately connected to the social, economic, and spiritual health of the child and of the family; and
  - insist on a strengths-based approach in recognizing and responding to a child's health needs.
- Families and providers in Napa and Sonoma Counties offer the following lessons to family-provider collaboration:
  - collaboration requires concentrated commitment, attention, and effort;
  - integrating family members into service delivery requires attention to implementation;
  - in working at collaboration, families and providers must be aware of the support (or lack of it) for collaboration on the part of other agencies; and
  - the CMHS grant structure provides extremely useful leverage for Child Mental Health Initiative sites working at collaboration.
- Mutual respect and collegiality are key components of East Baltimore's efforts at collaboration. In particular, East Baltimore has learned that family-provider collaboration requires:
  - respect, which in turn demands open communication, long term commitment to a process, and shared history; and
  - that providers in systems of care must respect family members as colleagues who bring expertise and competence to the collaborative relationship.

In East Baltimore, family members and providers stressed the importance of respect for each other in their collaborative work.

## DEFINITION AND COMPONENTS OF FAMILY-PROVIDER COLLABORATION

A summary of our findings regarding the definition and components of family-provider collaboration follows.

**Definition.** Family-provider collaboration in systems of care is the process that participants (including family coordinators and advocates, therapists, administrators, social workers, and case managers) in systems of care engage in to improve services for children and their families, and requires:

- ongoing dialogue on vision and goals;
- attention to how power (administrative, financial, etc.) is shared;
- attention to how responsibilities in planning and decision-making are distributed;
- open and honest two-way communication and sharing of information; and
- that all participants in systems of care are seen as mutually respected equals.

**Components.** Frequently mentioned components of family-provider collaboration in the literature review corresponded with our telephone interviews and sites visits, and include:

- a caring, non-blaming attitude toward the family;
- recognition of the family as a key resource;
- recognition of limits and the existence of other responsibilities;
- shared responsibility and power in the relationship, including joint decision-making and problem solving;
- support and understanding;
- practical assistance that improves families' access to services;
- open and clear information sharing; and
- professionals' readiness to alter services based on feedback from parents.

## CONCLUSIONS AND RECOMMENDATIONS

Family-provider collaboration in systems of care is a process unique to each community. Successful collaboration depends on long-term commitment of family members and providers to a common vision and set of goals. The primary objective of working at family-provider collaboration is to improve services for children and families. Participants in systems of care must constantly connect the work of collaboration to the question of how (or if) services are improving for children and families (according to those receiving services).

In conversations with participants in systems of care, and through visits to Child Mental Health Initiative sites, three components of collaboration repeatedly surfaced. We believe the following three aspects of families and providers working together are minimally necessary for collaboration:

- shared vision and goals,
- shared power in decision-making at all levels, and
- long-term commitment to the process of developing collaboration.

Collaboration occurs in a range of different ways and at a variety of levels in systems of care. Family-provider collaboration is simultaneously dependent on the existence of shared vision and goals, shared power, and long-term commitment, as well as on how families receiving services in that community define “improved services.”

Little research has been done on family-provider collaboration so many basic questions are yet to be resolved. Following are a few suggestions for beginning a research agenda in this area:

- define family-provider collaboration in operational terms, develop instruments to measure the construct at multiple levels of the system;
- how does family-provider collaboration impact the proximal and distal outcomes of the system of care at individual child, family and system level;
- how does the presence of family-provider collaboration effect family outcomes such as satisfaction with services, empowerment, ability to advocate for the child;
- are there predictable stages that systems of care go through in working toward collaboration;
- are there characteristics of communities or services systems that allows family-provider collaboration to develop more easily;
- are there ways in which family advocacy organizations can best support the development of family-provider collaboration within local systems of care; and
- does the presence of family-provider collaboration lead to a system of care that looks different with regard to the kinds of services provided, the way services are delivered and who delivers them.

The promising practices in family-provider collaboration that we include in this monograph demonstrate that collaboration is occurring. The conversations we had with participants in systems of care attest both to the benefits of and challenges to achieving collaboration. Collaboration, though difficult, is critical to improving services for children and families. We hope this monograph communicates the possibility and reality of promising practices in family-provider collaboration, as well as provides insight into achieving family-centered systems of care.

## Promising Practices in Family-Provider Collaboration: An Overview of the Monograph

### SECTION I: OVERVIEW AND SUMMARY OF OUR FINDINGS IN REGARDS TO FAMILY-PROVIDER COLLABORATION

### SECTION II: IN-DEPTH DESCRIPTIONS OF FOUR APPROACHES TO FAMILY-PROVIDER COLLABORATION

PEN-PAL and FACES  
North Carolina  
Mobilizing local communities  
for family participation

K'e Project, Navajo Nation  
Family, clan, and kinship  
central to system of care

Sonoma and Napa Counties  
Comprehensive System of Care  
Integrating family members at  
all levels of system of care

East Baltimore Mental Health  
Partnership, Maryland  
Developing a family-  
friendly system of care

### SECTION III: THIRTEEN PROFILES THAT FEATURE PROMISING PRACTICES IN FAMILY-PROVIDER COLLABORATION

Hawaii Ohana Project, Hawaii Families as Allies  
Broad participation of family member

Vermont Access Project  
Development of training to empower parents

Stark County Family Council, Ohio  
Training at all levels for everyone in system of care

Kan Focus and Parent T.E.A.M.S.  
Use of focus groups to support family participation

Kmihqitahasultipon Program, Indian Township  
Four-week intensive training program

Project Heartbeat, San Diego, California  
Support of family participation at all levels

North Dakota Partnership Program  
Family members as equal and regular partners

San Mateo County Mental Health  
Use of strengths-based assessment

Families Reaching in Ever New Directions, N.Y.  
Broad spectrum of families working in system of care

Dream Catchers Family Advocates, Ohio  
Working at achieving sustainability

Santa Cruz County Children's Mental Health  
Use of documents that support family participation

South Philadelphia Partnership Project  
Day camp designed and staffed by family members

Wraparound Milwaukee  
Family participation in writing mission statement





# Chapter I

## Overview and Discussion

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**Family-Provider Collaboration**—Family-provider collaboration in children's mental health services is the process that participants (including family coordinators and advocates, therapists, administrators, social workers, and case managers) in systems of care engage in to improve services for children and their families, and requires:

- ongoing dialogue on vision and goals;
- attention to how power is shared;
- attention to how responsibilities in planning and decision making are distributed;
- open and honest two-way communication and sharing of information; and
- that all participants in systems of care are seen as mutually respected equals.

Efforts at collaboration must occur at all levels of the system of care, including evaluation, program design and implementation, and delivery of services.

This monograph addresses family-provider collaboration in systems of care serving children with mental, behavioral, and emotional disorders and their families. Family-provider collaboration in systems of care has been defined as “working together or joining in the pursuit of a common goal” (DeChillo, 1993). Families of children receiving services, along with providers who have seen and continue to see the benefits of family participation in services, have been strong supporters of family-provider collaboration. As a result of ideas and assumptions prevalent in traditional mental health services, mental health professionals have in some cases held families responsible for their children's mental and emotional disorders. Moving from services that fault parents and reject their participation, to systems of care that value family participation at all levels, is a central challenge for participants in systems of care. This monograph features several policy and practice examples of how systems of care are responding to that challenge.

increasingly recognizing the value of family-provider collaboration in systems of care offering services to children with emotional, behavioral, and mental disorders and their families. Collaboration among families and providers can result in services:

- that respond to the particular needs of a local community;

System planners, policy makers, and practitioners are

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**Traditional Mental Health Services**—include services that are usually: (1) limited to outpatient, day treatment, and in-patient services; (2) prescribed by a professional with little or no family participation; and (3) categorically funded.

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- are strengthened by the expertise and input of a range of people concerned with children's mental health; and
- are family-friendly.

At the service delivery level, the degree of family participation in collaborative planning for their children's education and treatment has been connected to improved service coordination, and to successfully meeting children's needs (Koren et al., 1997).

In our conversations with family members and site directors, participants in systems of care repeatedly stressed that collaboration is a long-term process (rather than an event), and that working through issues

of developing respect, articulating goals and vision, and sharing power are critical components of family-

provider collaboration. Further, while there may be parallels among the practices, approaches, and strategies that service systems develop to achieve collaboration, participants within any one community are best able to shape family-provider collaboration within their system of care.

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*Developing respect, articulating goals and vision, and sharing power are critical components of family-provider collaboration.*

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Families and providers in systems of care are working together in collaborative ways. In our conversations with

participants in systems of care across

the United States, we found that promising practices in family-provider collaboration are numerous and range from effective training in family-provider collaboration to the difficult task of achieving respect among all participants within systems of care. In our discussions of the ways in which various systems of care have worked at the process of collaboration, the authors hope this publication serves as a resource and tool for participants in systems of care who wish to expand family-provider collaboration.

This monograph is one of several monographs being published in connection with the Child and Adolescent and Family Branch of the Center for Mental Health Services (CMHS), Substance Abuse and Mental Health Services Administration, as part of the Comprehensive Community Mental Health Services for Children and Their Families Program (known also as the Child Mental Health Initiative). The Center for Mental Health Services has awarded grants

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### **Participants in Systems of Care—**

Anyone who supports the development, evaluation, or delivery of services to children with emotional, behavioral, and mental disorders and their families, including family members, social workers, providers, site directors, and case managers. Support is broadly understood and includes education, advocacy, respite, identification and referral, assessment, development, and evaluation of services.

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**System of Care—**As stated in the grant *Guidance for Applicants*, a system of care is “a comprehensive spectrum of mental health and other support services which are organized into a coordinated network to meet the multiple and changing needs of children and adolescents with serious emotional disturbances and their families.”

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to more than 30 sites across the United States who applied for funds to improve systems of care for children. The Center for Mental Health Services has a clear directive to Child Mental Health Initiative sites that they implement family-provider collaboration within their systems of care. This directive provides a unique opportunity for communities to work at collaboration when offering services to children with emotional, behavioral, and mental disorders and their families. As the federal grant guidelines state, successful implementation of systems of care at the Child Mental Health Initiative sites depends on “the full involvement and partnership

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**G**rant guidelines emphasize “the full involvement and partnership of families in: (1) the planning, development, implementation, management and evaluation of the local service system; and (2) the care of their children and adolescents.”

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of families in: (1) the planning, development, implementation, management and evaluation of the local service system; and (2) the care of their children and adolescents” (U.S. Department of Health and Human Services, 1998). While the authors hope this monograph is useful to a range of participants in a wide variety of systems of care, it is particularly intended for communities, both current and future, who are looking for strategies to increase family participation in systems of care and to work at family-provider collaboration.

The first section of this monograph presents an overview of existing knowledge on issues

related to family-provider collaboration, drawing on the wealth of experience of family advocacy organizations and on published literature. The second section examines promising practices in family-provider collaboration at four Child Mental Health Initiative sites, addressing in an in-depth manner the process that participants in each of these systems of care have engaged. Finally, the third section of this monograph identifies a range of approaches that Child Mental Health Initiative sites have developed in addressing particular challenges to family-provider collaboration.

## BACKGROUND TO THE ROLE OF FAMILIES IN SYSTEMS OF CARE

As participants in systems of care work toward family-provider collaboration, they do so within a context that has not always valued family member involvement. Support for family participation in children's mental health has largely developed in the last 15 years, reflecting developments in health, disability, and human

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**Professionals**—People within a system of care who have had specific educational training concerning the delivery of services to children with emotional, behavioral, and mental disorders and their families.

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**Promising Practices in Family-Provider Collaboration**— A practice, strategy, or approach that participants in children's mental health systems of care have developed that: (1) leads to improved collaboration among family members and providers and that (2) ultimately supports family-centered services and improved outcomes for children. Promising practices are examples of collaborative processes that participants in systems of care are developing.

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service fields. Families and professionals who advocate for increased family participation continue to face hesitation and reluctance from participants within children's mental health systems of care (Allen & Petr, 1998).

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**Family Member**—A primary caregiver or adult with substantial and ongoing involvement in the life of a child who has (or the lives of children who have) emotional, behavioral, or mental disorders. This could include anyone who functions in the role of a family member, including parents, aunts, uncles, grandparents, siblings, fictive kin, and clan members.

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Participants working toward family-provider collaboration within their communities have been resourceful and creative, as models of and support for collaboration are still developing and to some extent lacking. Professionals who are working at collaboration likely received little training in the area of family participation in services; indeed, professional schools and programs may in some cases continue to blame and stigmatize families (Wahl, 1989; Hanley & Wright, 1995).

As families become involved in family organizations and in system change efforts, they do so with no guarantee that providers in their community will welcome their participation. Because service system planners and administrators retain primary access to and control of financial resources, family members are often faced with a lack of power to make the changes they think are needed. This lack of power contributes to family members occupying a tenuous position within children's mental health service delivery systems. In short, families committed to significant participation in their community's mental health system cannot be certain that providers will seek out, desire, or welcome that participation.

As participants in systems of care work toward collaboration, they do so within a framework where establishing respect and sharing power are the most difficult challenges to address and resolve. These issues surface between the two groups of families and providers, as well as within groups of family members and within groups of providers. Current efforts at collaboration follow years of providers' and researchers' lack of attention to family participation in systems of care. This section addresses the shift that has been made within systems of care from blaming families and resisting family involvement in services to valuing family participation.

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*As systems of care in children's mental health work toward collaboration, they do so within a framework where establishing respect and sharing power are the most difficult challenges to address and resolve.*

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## **Viewing Family Members as “Part of the Problem”**

For most of this century, providers and practitioners in systems of care offering services to children with emotional, behavioral, and mental disorders and their families have viewed parents and family members as at best extraneous and at worst a hindrance in the process of serving children with mental, behavioral, and emotional health needs. Particularly in the first half of this century, the provider often called in a family

member solely for the purpose of obtaining information. Providers often demanded hours of family members' time during which family members communicated particular information concerning the family, child, and family relationships. Often, providers would then seek out additional sources to confirm the family members' information. After this, family members frequently had no further connection to the child's care (Koroloff & Briggs, 1996).

## **Family Therapy as Treatment**

In the 1950s and 1960s, mental health care researchers and professionals began to question the virtual absence of family members from their own children's care. Researchers began to view family dynamics as having a major impact on the child's behavior, and family therapy emerged as important to treating children. Professionals brought in families to educate family members, and to better observe and likewise change family dynamics. Although the family therapy approach did include parents in the child's treatment plan, it most often did so with the assumptions of earlier theoretical models that families needed to be "fixed." Although families may have had access to mental health services and to their child's care, families remained external to the diagnosis and decision-making surrounding their child's care (Koroloff et al., 1996; Friesen & Koroloff, 1990).

## **Recent Shifts in Understanding Children's Mental Health**

Beginning in the early 1960s, parents of children with developmental disabilities and supportive professionals began lobbying state systems of care to provide more adequate services for their children. Parallel organizing within children's mental health services contributed to systems of care altering their delivery of services (Bryant-Comstock, Huff, & VanDenBerg, 1996). Significant shifts in children's mental health theory accompanied this organizing. Several studies in the 1970s critiqued schools of thought that identified parents as having primary responsibility for their children's health problems (Friesen & Koroloff, 1990).

Throughout the 1980s, parents and supportive professionals continued to organize and advocate for systems of care that offered services in respectful and relevant ways. While some professionals continued to blame families for their children's problems and exclude them from treatment and delivery of services, family members increasingly offered their experiences and ideas to the many conversations and exchanges going on at local, state, and national levels. Family members were questioning and in some cases not accepting the roles providers ascribed to and expected of them.

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## **Role of Families in Systems of Care**

<b>Mid-1900s:</b>	<b>Family members had little or no connection to child's care.</b>
<b>1950s-1960s:</b>	<b>Mental health professionals began to question the absence of families from their child's care. "Family therapy" as treatment became increasingly popular.</b>
<b>1960s-1970s:</b>	<b>Families of children with developmental disabilities began advocating for increased family participation in children's mental health services.</b>
<b>1980s:</b>	<b>Mental health professionals questioned belief that family members were responsible for their child's health problems.</b>  <b>Parents and supportive professionals continue to advocate for increased family participation in services.</b>
<b>1990s:</b>	<b>Systems of care offer services based on child and family strengths. Collaboration increasingly a goal of participants in systems of care.</b>

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Current knowledge and thought regarding children's mental health issues and services has changed significantly since the first half of the 1900s. Participants in systems of care generally acknowledge that biological, social, and psychological factors all impact children's mental, behavioral, and emotional health. Further, participants in systems of care understand the development of children's mental, behavioral, and emotional health needs as interactive and dynamic rather than linear (Friesen & Koroloff, 1990). Many systems of care choose to offer treatment based on child and family strengths. Increasing numbers of systems of care use a team-based approach to offer family-centered services to children and families; often, a family advocate will be a permanent member of that team, in addition to a family member (or members) of the child receiving services.

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**Family Advocate**—An individual who is a primary stakeholder in the well-being of children and who actively works to improve the delivery of mental health services to an individual family and their child (or children), and/or to change the mental health service delivery system so that it is family-centered.

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Changes in knowledge and theories related to children's mental health issues have affected the delivery of services to children and their families. At the same time, participants across service sectors, or even within any one system of care, rarely agree on how children are best served. Those involved in systems of care offering services to children with



emotional, behavioral and mental disorders and their families have different perspectives on collaboration. If and how family-provider collaboration occurs at particular children's mental health systems of care depends on a range of factors, including:

- the history of mental health services in that community and state;
- the type of education and training staff have received, particularly in regard to the role of the family in children's mental health services;
- the existence and history of family advocacy in the community and state; and
- the ongoing experiences and interactions of all participants in that system of care.

Family-provider collaboration is occurring in many creative forms, and participants in systems of care are working out new ways to provide services. After discussing the definition and components of collaboration, we will articulate lessons we have learned in our conversations and Child Mental Health Initiative site visits with participants in systems of care.

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### **Family-Centered —**

A system of care which is family-centered:

- supports all family members involved with the child's care; and
  - involves all family members in all aspects of planning and evaluating the service delivery system (including services for themselves and the services for their families).
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***F**amily-provider collaboration is occurring in many creative forms, and participants in children's mental health systems of care are working out new ways to provide children's mental health services.*

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## **DEFINITION AND COMPONENTS OF FAMILY-PROVIDER COLLABORATION**

Family-provider collaboration has been of particular interest to participants in systems of care offering services to children with emotional, behavioral and mental disorders and their families since 1984.

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***I**n our conversations with participants in children's mental health systems of care, it was clear to us that lessons learned about collaboration are guidelines and not formulas.*

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At that time, Congress authorized the National Institute of Mental Health to develop the Child and Adolescent Service System Program (CASSP). This program's primary objective was to improve services for children with serious emotional disturbances and their families. Critical components of this objective included support for family organizing and efforts toward collaboration.

While CASSP "recognized the need for extensive family involvement in the design and implementation of a system of care

for children who have serious emotional, behavioral, or mental disorders and their families" (Bryant-Comstock, Huff, & VanDenBerg, 1996), "extensive family involvement" was not accomplished easily.

Achieving family-provider collaboration is a community-specific process. While participants in systems of care continue to articulate components of collaboration that are generally relevant, the day-to-day process communities engage in as they work toward collaboration is unique. In our conversations with participants in systems of care, it was clear to us that lessons learned about collaboration are guidelines and not formulas. Family-provider collaboration is a process that occurs from within a particular system of care, emerging out of the work of a specific group of people. Family-provider collaboration is not an “answer” or “solution” that can be imposed from outside of the system of care. The following pages will address current definitions and components of family-provider collaboration.

## **Definition of Family-Provider Collaboration**

Collaboration is most simply defined as “working together or joining in the pursuit of a common goal” (DeChillo, 1993). More specifically, family-provider collaboration has been defined as a relationship “in which parents and professionals develop mutually agreed goals, share responsibilities in planning and decision making, are seen as mutually respected equals, and engage in open and honest two-way sharing of information” (Jivanjee & Friesen, 1994).

Family-provider collaboration in systems of care is the process that participants in systems of care (including family coordinators and advocates, therapists, administrators, social workers, and case managers) engage in to improve services for children and their families, and requires:

- ongoing dialogue on vision and goals;
- attention to how power (e.g., administrative, financial) is shared;
- attention to how responsibilities in planning and decision making are distributed;
- open and honest two-way communication and sharing of information; and
- that all participants in systems of care are seen as mutually respected equals.

Efforts at collaboration must occur at all levels of the system of care, including evaluation, program design and implementation, and delivery of services. The central purpose of collaboration is to improve services for children and families; we assume that “parents know what is best for themselves and their children” and that professionals’ “services exist to support parents as the primary agent in helping the child achieve his or her goals” (Huff et al., 1998).

In identifying what family-provider collaboration is, it can be helpful to understand particular challenges participants in systems of care face in working at collaboration. Comments from site directors and family coordinators indicated two levels of challenges, as illustrated in the table on the next page.



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## **Challenges to Family-Provider Collaboration**

### **Primary Challenges**

- A low commitment to and respect for the participation of family members in the system of care; and
- A lack of agreement among family members and providers on how collaboration is defined and practiced within a system of care, and more particularly, agreement on how power is shared.

### **Secondary Challenges**

- achieving trust and reducing suspicion
  - incomplete or uneven training in collaboration
  - reaching consensus on vision and goals
  - sustaining new roles and relationships
  - resistance to family participation from other service systems
  - sustainability of the family organization
  - concerns regarding confidentiality
  - the existence of tokenism
  - reflecting community norms in system of care
  - imbalance of power related to financial decisions
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It was clear to us that while the secondary challenges mentioned above are in fact challenges, they are at the same time rooted in deep-seated differences among participants within systems of care. These differences, which encompass attitudes and practices, are broadly related to understandings of the role of providers and the role of family advocates participating in systems of care, and to the meaning of collaboration in particular contexts. Family members and site directors at the Child Mental Health Initiative sites stressed that it is the willingness to address these fundamental differences that is critical to establishing and maintaining collaboration.

In thinking about collaboration, several terms are relevant to families and providers working together in systems of care. We believe it is helpful to view family involvement in services, family participation in services, and family-provider collaboration as three parts of a continuum. The concept of “family involvement” in services comes largely out of the family therapy model. In this framework, families served primarily as outside contributors to children’s mental health services; families were not central or even necessary to providing services. Providers chose to “include” family members in limited ways, affording families little if any significant role or input at the service system.

Family participation in services often indicates families have some level of influence that extends beyond token involvement in the system of care. In our conversations with family coordinators and providers, participants in systems of care often used the word “participation” as qualitatively different from involvement, connoting an important role in decision making. Family participation in services points to families working:

- at several levels of the system of care;
- in an independent family organization; and
- in staff positions that afford family members a role in the decision-making process.

Participants in children's mental health systems of care can take concrete steps to support and sustain family participation within a service system. Friesen and Koroloff (1990) point out that providers can encourage family participation in at least three ways. Providers can:

- develop and maintain a climate and opportunities for family participation;
- make it possible for family members to be full participants through sharing information and providing training; and
- offer concrete and practical support, including child care, transportation, and reimbursement for expenses and time taken off of work.

Family participation in systems of care will often require significant changes in planning and programming, and in the practices of individual clinicians. As parents contribute through participating in task forces and committees, on advisory boards at agency and community levels, and as participants in the evaluation of services, ongoing commitment to family participation on the part of all participants in the system of care will be critical for family-provider collaboration.

Improved services for children and their families is the primary objective for family participation in systems of care. The term family-centered services refers to the structure of a system of care, within which family participation and family-provider collaboration occur. Family-centered services minimally require ongoing expressions of family participation and family-provider collaboration. Family involvement, without family participation or family-provider collaboration, will not support family-centered systems of care.

Family-centered care “is based on the belief that the family has significant influence over an individual's health and well-being, and that because of this influence, families must be respected and supported in their roles as caregivers and decision-makers” (Institute for Family-Centered Care, 1998). As

Koroloff and Friesen point out, family-centered care emphasizes “the central role of the family in all aspects of service” (1997). In family-centered services, the responsibility of designing, implementing, and evaluating services is shared by providers and family members. The Institute for Family-Centered Care (1998) offers four “core principles” of family-centered care. In family-centered care,

- (1) people are treated with dignity and respect;*
- (2) health care providers communicate and share complete and unbiased information with patients and families in ways that are affirming and useful;*
- (3) individuals and family members build on their strengths by participating in experiences that enhance control and independence; and*
- (4) collaboration among patients, families, and providers occurs in policy and program development and professional education, as well as in the delivery of care.*

Family-centered services will most likely be offered in systems of care where family-provider collaboration is a priority.

This monograph focuses on family-provider collaboration as an ongoing process that occurs at many levels within a system of care. Our definition of family-provider collaboration comes out of conversations with participants in systems of care across the United States, as well as through examination of writing on family-centered practices in systems of care offering services to children with emotional, behavioral, and mental disorders and their families (Allen and Petr 1998; Bryant-Comstock, Huff, & VanDenBerg, 1996; Friesen & Huff, 1990; DeChillo, 1993; DeChillo, Koren, & Schultze, 1994; DeChillo, Koren, & Mezera, 1996; Jivanjee & Friesen, 1994; Bishop, Taylor, & Arango 1997; and Adams et al., 1997).

## **Components of Family-Provider Collaboration**

Participants in systems of care have identified a range of components important for collaboration. One list developed by DeChillo, Koren, and Merezaa (1997) summarizes 26 frequently mentioned elements into five characteristics:

- (1) a caring, non-blaming attitude toward the family;
- (2) sharing information;
- (3) recognition of the family as a key resource;

- (4) recognition of limits and the existence of other responsibilities; and
- (5) shared responsibility and power in the relationship, including joint decision making and problem solving (DeChillo, Koren & Schultze, 1994).

Following their survey of 455 family members caring for a child with a serious emotional, behavioral, or mental disorder, DeChillo, Koren and Schultze reported four distinct areas of collaboration between family members and professionals:

- (1) support and understanding;
- (2) practical assistance that improves families' access to services;
- (3) open and clear information sharing; and
- (4) professionals' readiness to alter services based on feedback from parents.

Following their survey of family members, DeChillo, Koren, and Schultze (1994) conclude that "the overarching characteristic of a collaborative relationship is the sharing of power and responsibility by the family and the professional."

The Federation of Families for Children's Mental Health has developed a list of value-based principles that are particularly relevant to the process of collaboration. These principles were developed with the belief that families and providers can work together and that collaboration will improve services for

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### **Value-Based Principles Important to Collaboration Developed by the Federation of Families for Children's Mental Health:**

- Children are children first, and special needs are secondary.
  - Families are not "dysfunctional," and the term dysfunctional is blaming and unnecessary.
  - Families are experts concerning their children.
  - Families should control decisions made about their child.
  - All participants in systems of care must respect the "rights, strengths, and individuality of each child or adolescent".
  - Services must be strength-based.
  - Services must be "available, affordable, accessible, and appropriate."
  - Families are "entitled to supports that will help them keep their children at home."
  - Family units are a "source of strength for children."
  - Services to children must be based on need and not on ability to pay.
  - Training of professionals "must be improved and expanded."
  - All participants in systems of care must "dare to dream" about what is possible for their children (Bryant-Comstock, Huff, and VanDenBerg, 1996).
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children. When working with the assumption that the central purpose of collaboration is to improve services for children and families, these value-based principles provide a helpful framework within which to think about the process of collaboration. Linking the components of collaboration with the value-based principles

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*The central purpose of collaboration is to improve services for children and families.*

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indicates the importance of keeping families' priorities and interests at the forefront in all collaborative efforts.

It is difficult to fully describe the commitment and effort that family-provider collaboration requires. Those who have worked at collaboration know it demands considerable time and energy, a willingness to take risks, and a

commitment to a long-term process. Friesen and Huff (1990) write, "Key to a successful collaborative relationship is an understanding that some conflict is likely to occur because of the differences of opinions and preferences between professionals and family members as well as differences within the two groups." Through our conversations with participants in systems of care, we learned that family members and providers committed to collaboration continue to work at articulation of vision and goals, power sharing, and how to address and resolve conflict. After discussing the method and organization of the monograph, we will describe what we have learned about family-provider collaboration.

## METHOD AND ORGANIZATION

The method the authors used in researching and writing this monograph drew heavily on the expertise of families and providers in Child Mental Health Initiative sites. In the second section, we discuss four Child Mental Health Initiative sites and the process of collaboration at those sites in an in-depth manner. A third section "profiles" 13 Child Mental Health Initiative sites, providing brief descriptions of strategies, approaches, and practices that sites have developed in working toward collaboration.

In writing this monograph, a central component of understanding family-provider collaboration was identification of the challenges that participants in systems of care face in achieving collaboration. After identifying a list of 2 primary and 10 secondary challenges, we distributed nomination forms to site directors and family coordinators at approximately 30 Child Mental Health Initiative grant sites. Family members and providers were invited to nominate Child Mental Health Initiative sites (their own and other sites) that had developed or were developing creative strategies and approaches to address the secondary challenges. Several promising practices emerged; the second and third sections feature examples of promising practices (rather than exemplary sites). Four in-depth discussions feature four different geographical and cultural settings; each of the four Child Mental Health Initiative sites offers unique insights into the complex process of collaboration. The thirteen profiles also represent geographic and cultural balance; these shorter pieces feature particular practices and approaches that Child Mental Health Initiative sites have developed in

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## Family-Provider Collaboration: The Method We Used

- **Compiled list of challenges:** Conversations with site directors and family coordinators helped us identify 2 primary and 10 secondary challenges.
- **Nomination process:** Which Child Mental Health Initiative sites, according to family members and providers, provided examples of promising practices in family-provider collaboration? We received numerous nomination forms.
- **Organization:**
  - (1) four in-depth discussions that explore the process of collaboration; and
  - (2) thirteen profiles that offer practical resources and ideas in response to particular challenges.
- **We sought to:**
  - (1) maintain geographic and cultural balance;
  - (2) provide examples of promising practices (and not exemplary, or “perfect sites”); and
  - (3) feature CMHI sites that each offer different and unique insights.

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responding to specific challenges. In our interactions with systems of care, promising practices in family-provider collaboration were plentiful, but there were no Child Mental Health Initiative sites that were always and completely collaborative.

Critically important to this process were ongoing conversations with many family coordinators and providers working at the Child Mental Health Initiative sites, as well as with other participants in systems of care. The knowledge and experiences shared through phone interviews and site visits run throughout this monograph. In addition to the Child Mental Health Initiative sites featured in the next two sections, many family coordinators and providers at other Child Mental Health Initiative sites generously offered insight and wisdom on the topic of family-provider collaboration. In much the same way that family-provider collaboration in systems of care is a process, rather than an isolated event or action, the input we received from participants in children's mental health services over the course of writing this monograph significantly influenced our learning and conclusions.

The final part of this overview and discussion section features the lessons we have learned in our work on the topic of family-provider collaboration. While collaboration is a challenging process, we remain encouraged and hopeful as we continue learning about the significant work that participants in systems of care are contributing to family-provider collaboration. In featuring the efforts and accomplishments of different systems of care, it became clear that many Child Mental Health Initiative sites, if not all, have developed ways to be collaborative.

The second section of the monograph discusses the work of collaboration at four Child Mental Health Initiative sites representing four different geographical and cultural settings (i.e., rural, Native American, small city/county, and urban), including:

- the *PEN-PAL* and *FACES* Projects in North Carolina
- the *K'e Project* on the Navajo Nation in New Mexico, Utah, and Arizona
- the *Napa and Sonoma County Systems of Care* in California
- the *East Baltimore Mental Health Partnership*, in Maryland

The third section of this monograph profiles examples of promising practices at 13 Child Mental Health Initiative sites. We hope that our learning, as well as our discussion of family-provider collaboration in children's mental health services, serves as a resource to anyone interested in family-provider collaboration in children's mental health systems of care.

## **PROMISING PRACTICES AT FOUR CHILD MENTAL HEALTH INITIATIVE SITES**

Conversations with participants in systems of care, as well as visits to Child Mental Health Initiative sites, repeatedly demonstrated to us that working at family-provider collaboration and family-centered services is a process. Collaboration occurs in a variety of ways. Further, collaboration in one area or project does not guarantee collaboration in all interactions or services at a particular mental health service system. Participants in systems of care in Napa and Sonoma counties (California), the Navajo Nation (New Mexico, Arizona, and Utah), *PEN-PAL* and *FACES* (North Carolina), and *East Baltimore Mental Health Partnership* (Maryland) are committed to changing children's mental health sites so that families are central to the system of care and so that families and children are better served. At each of these four Child Mental Health Initiative sites, change continues to be a process; indeed, participants at these sites were generous with insights regarding accomplishments and challenges.

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*While collaboration is a challenging process, we remain encouraged and hopeful as we continue learning about the significant work that participants in systems of care are contributing to family-provider collaboration.*

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### **PEN-PAL and FACES, North Carolina**

In Pitt, Edgecombe, and Nash counties, North Carolina, families and providers are particularly aware of the importance of the following to family-provider collaboration:

## **Family-Provider Collaboration: Lessons Learned A Summary of Four Child Mental Health Initiative Sites**

### **1) PEN-PAL and FACES, North Carolina**

Importance of:

- local family organizing
- perseverance
- willingness to try again

### **2) K'e Project, Navajo Nation**

Navajo philosophy and values support family-centered services by:

- understanding families as central to children's health
- insisting on strengths-based approach in working with children and families

### **3) Napa and Sonoma Counties, California**

Lessons learned:

- Collaboration requires commitment and effort.
- Families and providers must be aware of how other agencies view collaboration.

### **4) East Baltimore Mental Health Partnership, Maryland**

Family-provider collaboration requires:

- respect, open communication, shared history
- that providers view family members as colleagues.

- local family organizing as a key component in meeting the unique needs of the community; and
- perseverance and a willingness to try a variety of avenues to accomplish a particular objective.

Site directors and family coordinators emphasized the benefit of local family organizing to the delivery of services. Strong ties to local families and organizations support an awareness of strengths, needs, and social norms within particular communities. Further, family coordinators and site directors underscored the value of perseverance. Despite the best efforts on the part of family coordinators and providers to achieve a certain outcome, these efforts may result in frustration rather than success. When the process runs into walls, participants in North Carolina service sites stressed the necessity of a willingness to begin again, perhaps several times.

## ***K'e Project, Navajo Nation***

On the Navajo Nation in New Mexico, Arizona, and Utah, staff at the *K'e Project* work in a context where Navajo philosophy and culture are more predominant than the assumptions and beliefs embedded in non-Navajo approaches. The *K'e Project* is a profound example of one system of care that values family-



centered services. The project's closeness to Navajo values and tradition supports a vision of families as central to children's healing process. In Navajo culture and healing practices, the split between "family" and "provider" that is prevalent in non-Native cultures has little relevance. In working toward family-centered services, *K'e Project* staff have learned the value of *K'e* philosophy and Navajo values to sustaining family-centered children's mental health services. In particular, Navajo traditional approaches to healing:

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*In Navajo culture and healing practices, the split between "family" and "provider" that is prevalent in non-Native cultures has little relevance.*

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- understand the family as central to a child's health and well-being;
- view the child's mental, behavioral, and emotional health as intricately connected to the social, economic, and spiritual health of the child and of the family; and
- insist on a strengths-based approach in recognizing and responding to a child's health needs.

Staff at the *K'e Project* repeatedly returned to the importance of knowing families as the primary agents in children's emotional, behavioral, and mental health and well-being. Similarly, *K'e Project* staff offer services that acknowledge the reality of the family and child, and work within that context to offer support and resources for the child's healing.

## **Napa and Sonoma Counties, California**

Families and providers in Napa and Sonoma Counties offer the following lessons to family-provider collaboration:

- Collaboration requires concentrated commitment, attention, and effort.
- Integrating family members into service delivery requires attention to implementation.
- In working at collaboration, families and providers must be aware of the support (or lack of it) for collaboration on the part of other agencies.
- The Center for Mental Health Services (CMHS) grant structure provides extremely useful leverage for Child Mental Health Initiative (CMHI) sites working at collaboration.

Family-provider collaboration necessitates that participants in systems of care build relationships, address and resolve conflict, and stay focused on goals, all of which call for ongoing commitment to a process. Family members who work within the system need ongoing education and support (particularly from other family members). Further, collaboration requires that family members and professionals work at collaboration in an environment that is relatively safe for family participation and that affords the time necessary to achieve collaboration. Finally, participants in the Napa and Sonoma county systems of care

stressed the value of a grant that mandates family participation. In requiring family participation, the Center for Mental Health Services grant both legitimizes family-provider collaboration, and in turn provides considerable leverage for the site in their community.

## **East Baltimore Mental Health Partnership, Maryland**

Mutual respect and collegiality are key components of East Baltimore's efforts at collaboration. In particular, East Baltimore has learned that family-provider collaboration requires:

- respect, which in turn demands open communication, long-term commitment to a process, and shared history; and
- that providers in systems of care must respect family members as colleagues who bring expertise and competence to the collaborative relationship.

In East Baltimore, family members and providers stressed the importance of respect for each other in their collaborative work. Further, participants at the *East Baltimore Mental Health Partnership* articulated the value of providers' viewing family members as colleagues in children's mental health services. When providers choose to view and treat family members as true colleagues, they are significantly departing from traditional mental health services, and they are profoundly supportive of collaboration.

## **DISCUSSION**

Participants in systems of care are finding new ways to work together. As families and like-minded professionals continue to assert the value of family participation in children's mental health services, systems of care are increasingly characterized by partnerships with families. Families and providers are finding ways to interact that are respectful and collaborative. Family participation in systems of care changes how services for children with emotional, behavioral, and mental disorders and their families are conceptualized and delivered.

Family-provider collaboration is never a given. Participants in systems of care have found that meaningful and ongoing movement away from attitudes and actions that blame and devalue families can be difficult to accomplish and sustain. Systems and people change slowly. Frequently, participants within a service system change at different paces and in various rhythms. Delivery of services that used to be straightforward and obvious may seem complicated and ambiguous. Discomfort and tension may seem too often present.

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*When providers choose to view and treat family members as true colleagues, they are profoundly supportive of collaboration.*

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Family-provider collaboration occurs when participants in systems of care are ready to work at change. The next section offers four examples of how four Child Mental Health Initiative sites approach collaboration. All four of these examples demonstrate the belief that the best way to serve children and

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*Family participation in systems of care changes how services for children with emotional, behavioral, and mental disorders and their families are conceptualized and delivered.*

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families is through family-centered services. For three of the four sites, (Napa and Sonoma counties, East Baltimore, and North Carolina), family-provider collaboration is a critical component in moving toward family-centered services. At the *K'e Project* on the Navajo Nation, family-centered services are achieved through a return to Navajo traditional culture and healing practices. After discussing each of the four site's contributions toward family-provider collaboration and family-centered services, we conclude this section with specific attention to components and dimensions of family-provider collaboration.

## **DIMENSIONS OF FAMILY-PROVIDER COLLABORATION**

Family-provider collaboration in systems of care is a process unique to each community. Successful collaboration depends on long-term commitment of family members and providers to a common vision and set of goals. The primary objective of working at family-provider collaboration is to improve services for children and families. Participants in systems of care must constantly connect the work of collaboration to the question of how (or if) services are improving for children and families (according to those receiving services).

In conversations with participants in systems of care, and through visits to Child Mental Health Initiative sites, three components of collaboration repeatedly surfaced. We believe the following three aspects of families and providers working together are minimally necessary for collaboration:

- shared vision and goals
- shared power in decision making at all levels
- long-term commitment to the process of developing collaboration

Collaboration occurs in a range of different ways and at a variety of levels in systems of care. Family-provider collaboration is simultaneously dependent on the existence of the three principles above, as well as on how families receiving services in that community define "improved services."

## Shared Vision and Goals

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*The primary objective of working at family-provider collaboration is to improve mental health services for children and families.*

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Participants in systems of care rarely, if ever, come to the table with similar backgrounds, experiences, assumptions, expectations, and hopes for services and supports in a particular community. Family-provider collaboration requires agreement to work toward a common vision and goal; it often means agreeing to disagree. Bringing together a variety of assumptions and

expectations is a critical component of this process.

According to conversations with participants in systems of care, agreement on vision and goals is never automatic, and cannot be assumed. Lack of attention to vision and goals can result in sharp differences and tension surfacing among participants. This can occur at the beginning of collaborative efforts, or well into the process. Vision and goals often differ not only between families and providers, but among families and among providers. When differences in vision and goals become apparent, a give-and-take process is important. Attention to vision and goals must be ongoing; people change, and evaluation of delivery of services will and should influence vision and goals.

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*Vision and goals often differ not only between families and providers, but among families and among providers.*

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Family-provider collaboration requires an awareness of the range of visions and goals held by participants in a system of care. In our conversations with participants in systems of care, families and professionals found it helpful to ask the following questions:

- How are these goals directly related to improving services for families and children?
- How are current service system structures and funds related to our goals and vision?
- Do the vision and goals represent input from a range of community members?
- Do we have a process to keep our vision and goals current?

## Shared Power in Decision Making at All Levels

Currently, systems of care rarely afford the same amount and kind of power to families as they do to providers. Power, in relation to administrative, financial, and programmatic decision making, is centrally important to services to children with emotional, behavioral, and mental disorders and their families. Equally important is attention to power at the level of service planning, implementation, and evaluation for individual children and their families. Family-provider collaboration begins when participants within a system of care

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*Several participants in systems of care articulated the importance of patience, as well as the significant time required for conversations that often occur outside of the usual work structure.*

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have open and frank conversations about power and how it can be shared. This discussion begins with the recognition that until recently, families have had few avenues for influencing the way services and supports are designed and delivered.

In some cases (in regard to board membership, for example), shared power may imply a “50-50” kind of arrangement.

Shared power at all levels of a system of care, however, goes beyond 50-50 equations. Family-provider collaboration requires that participants in systems of care address and act on sharing power, always recognizing that families and providers alike bring valuable expertise, resources, and knowledge to the discussion.

## **Long-Term Commitment**

Achieving family-provider collaboration involves commitment to an ongoing development process. In our conversations with participants in systems of care, we were struck by the number of people who recognized that the collaborative process involves setbacks, frustrations, conflict, and inconveniences. Family-provider collaboration rarely occurs “on a schedule.” Several participants in systems of care articulated the importance of patience, as well as the significant time required for conversations that often occur outside of the usual work structure. Collaboration rarely occurs when participants within a system of care assume family-provider collaboration will be quick and easy. Family-provider collaboration is supported by participants in systems of care who understand and act on the commitment necessary to meaningfully address and work out issues related to shared values and goals and to shared power.

Promising practices in family-provider collaboration, as evidenced by the following two sections, are evident in service systems across the United States. Families and providers are working out ways to move outside of a traditional mental health model, and recognizing that families and providers’ contributions to systems of care are all profoundly important to the health and well-being of children, families, and communities.



# Chapter II

## Promising Practices at Four Children's Mental Health Sites

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### NORTH CAROLINA PEN-PAL AND FACES

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#### North Carolina PEN-PAL and FACES: An Overview

##### APPROACH

Establish local independent family advocacy organizations in each community.

##### PROMISING PRACTICES

Working together to mobilize local communities:

- recognition of unique characteristics of each community and the need for unique responses;
  - willingness to learn from past experiences and to experiment with new forms of partnership;
  - creative use of Community Collaboratives and service testing; and
  - use of a "system of care protocol" that binds signers to its principals.
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### History and Background

North Carolina is a state with a history of providing a broad array of effective services to children with serious emotional disorders and their families, although some feel that these services are unevenly developed throughout the state. The efforts of the Robert Wood Johnson-funded projects in several locations left a legacy of adherence to many systems of care principles in those areas involved (with the exception of "Families As Partners"). This, combined with early involvement in the Child and Adolescent Service System Program (CASSP), resulted in a state service system that is concurrently very progressive in some parts of the state and somewhat conservative in others. With 40 Area Mental Health, Developmental Disabilities and Substance Abuse Services Programs (MH/DD/SAS), governed by local boards and 100 counties, it is not surprising that services vary. With regard to the Center for Mental Health Services Child Mental Health Initiative, North Carolina has received two site grants. The first involved three counties and two Area MH/DD/SAS programs, Pitt Area and Edgecombe-Nash Area Programs. The Pitt-Edgecombe-Nash Public-Academic-Liaison (*PEN-PAL*) was funded in February of 1994 and currently is in its fifth and final year. The second Center for Mental Health Services grant was funded in

October 1997 and is located in four Area Programs, covering a catchment area that includes nine counties. This initiative, titled North Carolina Families and Communities Equal Success (NC-FACES), builds on the experiences and subsequent learning from the first grant.

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*The model of family organizing that is now favored in the North Carolina CMHS sites is to establish and nurture regional or local family advocacy organizations that spring from the interests of local family member leadership.*

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Family organizing in North Carolina dates back to 1989 when the North Carolina Alliance for the Mentally Ill (NC-AMI) established NC AMI-CAN (Child and Adolescent Network) as a unit within the state chapter. The family advocacy movement in North Carolina continued under these auspices for several years, receiving several years of funding from Center for Mental Health Services through the statewide family organization grants. Eventually, North Carolina *Families CAN* emerged, still under the fiscal agency of NC- AMI, later with the Mental Health Association in North Carolina and finally as an independent non-profit organization.

The major philosophy toward family involvement and family advocacy within the formal mental health system has been to support a separate and independent family advocacy organization that exists outside of both community and state-level mental health structures. More recently, the mental health planners and family members within North Carolina Center for Mental Health Services sites have expanded their objectives to include local, independent family organizations to meet the service and advocacy needs of local area families. This may be augmented by a statewide organization that works directly with policy makers and planners. However, the model of family organizing that is now favored in the North Carolina Child Mental Health Initiative sites is to establish and nurture regional or local family advocacy organizations that spring from the interests of local family member leadership.

The rest of this profile will describe two organizing efforts within North Carolina. First, we will describe the progression of efforts that led up to the recent establishment of a local family organization in the Pitt-Edgcombe-Nash area. Second, we will discuss the emergence and workings of a family-driven system of care in the Blue Ridge area, a North Carolina Families and Communities Equal Success (*FACES*) site.

## **Description of Partnerships between Family Members and Providers**

The process of building trust and a shared vision between family members and providers in this state has gone through a number of phases in which different family organizing approaches were tried, didn't work, or worked partially, and new approaches were developed. The string that binds this all together is a



strong shared commitment to involving family members at all levels of the system and a mutual agreement between family members and providers to persevere toward this goal, even when conflict and personal differences interfere. We will discuss this process separately for the two grants.

### **Pitt-Edgecombe-Nash Public Academic Liaison (PEN-PAL)**

The evolution of family provider collaboration involved a sequence of developmental activities that resulted in the recent establishment of With Every Child And Adult Reaching Excellence (*WE CARE*), a regional family advocacy organization that serves both Pitt and Edgcombe-Nash Areas. For the first three years of the Center for Mental Health Services grant, family advocacy and involvement was organized through North Carolina Families Child and Adolescent Network, originally developed as a program within the North Carolina Alliance for the Mentally Ill -Child and Adolescent Network. Because of a series of difficulties arising from conflicting organizational goals and management styles, North Carolina Families Child and Adolescent Network changed to a new fiscal agent—Mental Health Association of North Carolina—with subcontracts to its local affiliates in Pitt City and in Rocky Mount. Similar difficulties arose in this configuration, despite repeated attempts to provide technical assistance and management support. It soon became clear that critical family advocacy and support services were not being adequately provided to families in the *PEN-PAL* Project. Again, organizational goals and management style were not consistent with a local family-driven agenda. Finally, the family advocates, other involved family members, and state mental health leaders decided to pursue the possibility of supporting regionally based family organizations made up of family members from the local area. This resulted in the birth of *WE CARE*, located in Greenville.

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*At least one conclusion drawn from this experience was that it was difficult to meet local families' needs and gain their trust if the family advocacy program was in an office several hours' drive away.*

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At least one conclusion drawn from this experience was that it was difficult to meet local families' needs and gain their trust if the family advocacy program was in an office several hours' drive away, or more particularly, located in the State Capitol, automatically arousing a certain level of distrust. *WE CARE* emerged about half-way through Year 4 of the first Center for Mental Health Services grant. It is now operating out of its own offices in Greenville and Rocky Mount, providing family advocacy and family support services to both Pitt and Edgcombe-Nash. A core group of six or seven family members, led by Sandra Spencer, has organized a board and applied for independent status. Currently, *WE CARE* has office space that houses the director (Sandra Spencer), a full time office manager, and three Family Advocates. Two part-time Advocates work with families from Edgecombe-Nash and have offices in that area, and one full-time Advocate focuses on Pitt.

*WE CARE* leadership decided that several resources would be of immediate use to families in the community. *WE CARE* offers a computer room that features Internet access and an opportunity for computer skills enhancement. They also support a small lending library for families and have an ongoing supply of donated children's clothing. The family advocates in *PEN-PAL* now function as the data collectors in conjunction with Area Program (mental health) personnel, a role that allows them access to a broad array of families. According to Sandra, the family advocates get a more accurate assessment of service satisfaction from families than might other interviewers.

Although Sandra and the *WE CARE* board have been very creative in finding in-kind resources, a primary concern for this new organization is finding ongoing funding, particularly funding that does not compromise the organization's mission by forcing staff to focus on limited activities. For example, some funding should continue to be available through North Carolina's Title IV-B Training Plan, but this can only be used to support training activities. The most difficult component of the organization's work to find funding for is the front-line work, including one-on-one advocacy and support with families. It seems logical that at least some of these activities should be supported by the area mental health programs; however, in a state with increasing managed care activities, this is still under discussion. According to Mark O'Donnell, Research Director and Assistant State Project Manager, the continued success of *WE CARE* is an important outcome for the *PEN-PAL* grant. "If *WE CARE* doesn't survive, then we have failed. If there isn't a living family advocacy organization out there to help families promote positive change, we will have significantly blown it."

The future of *WE CARE* as a regional organization is precarious. Funding is secure until January, after which Sandra estimates she needs a minimum of \$100,000 a year to keep the organization functioning at a skeletal level, and \$250,000 a year to maintain the current activity level. This may be one of the limitations of developing local or regional family advocacy organizations. Each must go through developmental steps as an organization before it reaches maturity and is able to sustain itself. In addition, there is a question about how many independent local or regional family advocacy organizations can find stable funding within current state and foundation resources. A shared vision of the state office staff and *WE CARE* is the development of a strong coalition among family organizations in North Carolina, one that can effectively advocate across the state and secure ongoing funding.

The early work of Families Child and Adolescent Network should not be underestimated. The organizing that was done in the western part of the state resulted in Western North Carolina Families Child and Adolescent Network, a group of parents that went on to become very active in Families and Communities Equal Success, the second Center for Mental Health Services grant. Families Child and Adolescent Network has since changed staff, become an independent organization, and continues to

provide training to families through support from state mental health and the Title IV-B Training Plan. They currently have the contract to provide family advocates in two of the three counties at the Sandhill *FACES* site.

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*A critical question concerns the potential of the statewide organizational model for family advocacy organizations.*

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A critical question concerns the potential of the statewide organizational model for family advocacy organizations. If individuals with different skills and support had been involved, could the statewide organization model of family organizing have worked to provide service to the PEN PAL sites? In the opinion of at least one state level staff, the answer is twofold.

Yes, from a state point of view the model of a single, statewide organization is effective because it supports the need for a strong advocacy presence in the state capitol. At the same time, the development of advocacy organizations at the local or regional level is a better way to meet the goal of providing front line services to families who need support and case advocacy. These two sets of tasks have very different goals which might be accomplished by a well established, generously funded statewide organization with strong managers and good local contacts. Without these resources, growing smaller regionally or locally based family advocacy organizations run by local parents who are currently receiving services is believed to more effectively promote the values and beliefs of families and, as such, is the option being pursued in both PEN PAL and *FACES*.

### **North Carolina Families and Communities Equal Success (NC-FACES)**

Several key changes were made in the second proposal to the Center for Mental Health Services, based on learning from the Pitt-Edgecombe-Nash Public Academic Liaison project:

- It was recognized that the family organizing and advocacy had to come from the local area, and involve local families.
- The method of hiring and supervising data collectors was changed, moving the authority for these activities out of the state office and to the local sites.
- The state recognized that administering the funding from the state office was not promoting the autonomy and innovation hoped for, and so the funding was devolved to the local sites.

When staff at the state level began to think about identifying expansion sites for the second phase of grant activities, they began by identifying individuals in the geographic region who had a vision of the system of care and who had leadership ability to carry it out. According to Martha Kaufman, State Project Manager, these individuals did not need to be within the mental health service system but could reside in any part of

the system or within the family leadership. It is within the context of these experiences that North Carolina *FACES* was implemented. The discussion in this section will focus on the Blue Ridge *FACES* site, one of four that is being developed.

The Blue Ridge *FACES* site members have named themselves Families, Agencies and Communities Together (FACT). This region of North Carolina was one of the original Robert Wood Johnson sites and the legacy of that effort was still alive in the thinking of many providers in the community. As an introduction, Martha Kaufman and her staff held a Community Mobilization meeting in Blue Ridge using a process developed in Hawaii called "Together We Can." Two to 300 hundred people attended this meeting, underscoring the strong interest in the community for changes to the service system. As a follow-up to these activities, the state invested seed money for the community to use as it wanted as a way of preparing itself for the development of a system. This money was used to hire a family member in a part-time position to begin bringing community members together to plan the system of care. In addition, service testing or Coordinated Practice Reviews were conducted in the region. This approach allows for in-depth assessment of how the service system is working from several different vantage points, including that of the families receiving the service. This information was useful as the service system began to take a new shape.

*FACT* is a good example of a family-driven system of care. A small family advocacy and support group, Western North Carolina (WNC) Families Child and Adolescent Network (*Families CAN*), existed in Buncombe County when the Community Mobilization meeting was held. This small group of families were very motivated by their dissatisfaction with the services they had received. They came to know each other through community and church activities, and chance meetings in the waiting rooms at various agencies. They began meeting for support and soon began to develop an agenda related to changing the way services were delivered in the county. When money became available through the Area Program using resources provided to them by *PEN-PAL*, the Department of Social Services agreed to match those provided by State Mental Health for early Pitt-Edgecombe-Nash Public Academic Liaison expansion efforts. The initial work of Western North Carolina *Families CAN* with the local agencies led to an agreement to use these resources to hire a part-time family advocate. Karen Lohr was hired and began to coordinate the work of developing a system of care in Buncombe County.

With Karen as part-time family advocate and staff to the committee, a group of agency representatives and family members began to meet every other week to work out differences, resolve past grievances, and begin to outline a system of care. Karen notes that this group took the system of care literature literally and expected that half the group would be family members. In fact, she reports, meetings weren't held if family members weren't present. This group of individuals continued to meet for over a year working as partners with the state in system-of-care expansion. One of their tasks was to write

Memoranda of Agreement that all would sign regarding their responsibility for carrying out the philosophy of the system of care. Early on, the group recognized that there would be difficult times in the group process

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*Early on, the group recognized that there would be difficult times in the group process and agreed to continue to work together despite the conflict.*

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and agreed to continue to work together despite the conflict. Karen says that this commitment became explicit shortly after the group began meeting, and that it is one of the ground rules that allowed them to persevere. At the end of the year, the group had become a strong team in which family members were equal partners. Karen notes that the group had decided to implement a system of care in their county, whether or not the Center for Mental Health Services

grant was funded. This gave them the impetus to move ahead rather than waiting to see whether the money would be available. Consequently, when funding was received, this group was in a good position to use it effectively.

Blue Ridge was selected as one of the expansion sites under North Carolina *FACES*. Karen Lohr applied and was appointed the site director. She then hired another family member to take her place as family advocate. Finally, one of the two people hired to manage the data collection is a family member, giving this site an unusual cadre of family members with staff positions. The *FACT* site is a separate entity from the local mental health agency or other social services. *FACT* manages the Community Collaborative to which all local agencies, many independent contractors, Western North Carolina *Families CAN*, the local college and many individuals belong. Membership in this Community Collaborative binds the participants to working under the philosophy of system of care. *FACT* has developed a system of care protocol that each member has signed. This allows families to know that when they approach a collaborative member for services, they can expect to be treated in a manner consistent with the system of care philosophy, including being involved as an equal partner in the treatment of their child. Family members who are not treated in this way can complain to the agency director. *FACT* is responsible for training all the staff of Collaborative agencies in the system of care protocol and for educating families about this expectation.

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*The Community Collaborative, WNC Families CAN, and FACT are respected in the community.*

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The Community Collaborative has become an important entity in Buncombe County. Individuals are now bringing other service system issues to the Community Collaborative to solve. Recently, the lack of respite services was raised. This was brought to the Community Collaborative where, after discussion and broad input, a solution to developing respite care that was locally derived and locally acceptable was developed. The Community Collaborative, Western North Carolina *Families CAN* and *FACT* are respected in the community and perceived as well organized and rational, not just a “group of zealot parents” says Karen.

Western North Carolina *Families CAN* is now a thriving local family advocacy organization with independent status. It organizes parent support groups, parent-to-parent support, information and training for parents in the county. *FACT* exists as a separate entity although the two organizations are co-located at Mars Hill College in donated space. Many of the staff of *FACT* are also members of Western North Carolina *Families CAN*. *FACT* has begun to develop a Community Collaborative in Madison County where, according to Karen, they have already identified a strong and diverse group of family members. Eventually, Community Collaboratives will be developed in several other counties within the Blue Ridge site. In each case, a process that approximates the year's worth of meetings that happened in Blue Ridge will be put in place.

**Potential for Replication.** Several key elements have come together to make a family-driven system of care like *FACT* possible:

- There is strong support for family and professional collaboration starting at the top with Lenore Behar, Chief of Child and Family Services Section for the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (MH/DD/SAS), and Martha Kaufman, State Project Manager for Pitt-Edgecombe-Nash Public Academic Liaison and *FACES* and her staff.
- There was a legacy of cross-system cooperation and a group of persistent and very motivated families in Buncombe County who were willing to put in the time to reach a collaborative solution.
- The individuals involved were willing to reflect and change based on the lessons learned with *PEN-PAL*.
- Several family members who had skills and experience in administration and community organization were available to take key positions within *Families Agencies and Communities Together*.
- Families and professionals were able to take a long period of time (over a year) to meet together, resolve past grievances and work out a common vision of what their system of care should look like.
- The literal interpretation of the system of care literature led to involvement of families as 50 percent of the group consistently throughout the process.
- The fledgling family organization, Western North Carolina *Families CAN*, was in place and beginning to grow as this process was initiated, giving support and substance to the family side of the enterprise.

The question of whether *FACT* could be replicated in another Center for Mental Health Services site is a complex one. Certainly the individuals involved with *FACT* feel that this is a repeatable process. Already, they have developed a family group and are beginning a community collaborative in another county and will repeat this process in several more. Karen Lohr notes that she doesn't think the Community



Collaborative needs a whole year of meeting together before the system of care begins; however, she does think a period as long as six months may be necessary. Certainly, the availability of family members who have the background, experience and interest in applying for the position of site director would be another key element in replicating the *FACT* experience.

## ***K'E PROJECT, NAVAJO NATION***

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### **The *K'e Project*, Navajo Nation: An Overview**

#### **APPROACH**

Support Navajo traditional culture and values.

#### **PROMISING PRACTICES**

Centrality of *K'e* philosophy to system of care; recognition of family, clan and kinship as primary to children's health and well-being:

- program structure and delivery of services based on *K'e* philosophy;
- commitment to a process at levels of goals and mission, delivery of services, and staff development; and
- community-based and culturally competent system of care, through attention to language and cultural values.

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The *K'e Project*, working under the auspices of the Children and Families Advocacy Corporation (CFAC), is located in Arizona, New Mexico, and Utah. The project serves the Navajo Nation and is a community-based system of care that offers services out of six offices. *K'e*, a complex and intricate worldview that runs throughout Navajo culture and life, assumes the centrality of family, clan, and kinship to the well-being of individuals and society. In a broad sense, *K'e* supports "reverence for all things in the universe . . . balance and harmony." At a more specific level, *K'e* becomes the "central process of healing" as a "child's identity is defined, preserved, and protected through family relationships." The *K'e Project*, because of its considerable and ongoing attention to the relevance of the *K'e* philosophy to the services it offers families and children, offers valuable and unique insights to the process of family-provider collaboration.

The *K'e Project* began receiving Center for Mental Health Services funding in late 1994. Several members of the Navajo Community Advocacy Committee, an umbrella organization linking several Navajo Nation, federal, and non-profit groups, initiated the grant application process. The committee saw an

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*K'e, a complex and intricate worldview that runs throughout Navajo culture and life, assumes the centrality of family, clan, and kinship to the well-being of individuals and society.*

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opportunity to expand services to children and their families on the Navajo Nation, and to reintroduce Navajo traditions and understandings of health care into Navajo mental health services. Currently, the CFAC/*K'e Project* is governed by a 10-member Board of Directors, seven of whom are parents or consumers of the *K'e Project*. *K'e Project* offices, located in Chinle, Dilkon, and Fort Defiance (Arizona), and in Crownpoint, Tohatchi, and Shiprock (New Mexico), have five to six staff working at each office. In addition to being a rural population, the Navajo Nation is heterogenous, experiencing differences in religion, history, and culture among the Navajo people.

The *K'e Project* relies primarily on Navajo concepts of health and well-being in its delivery of services to children and families. Navajo approaches to children's health and well-being understand the family as central to children's mental health. In a Navajo context, the split between family and provider has little relevance. *K'e* philosophy and values offer insight into family-provider collaboration because they have developed outside of and separate from the traditional mental health model prevalent in the dominant culture. Whereas the concept of family-provider collaboration is necessary because of stigmatization and devaluing of families, the *K'e Project* begins in a cultural context which fundamentally values families and their participation in their children's healing.

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*Navajo approaches to children's health and well-being understand the family as central to children's mental health.*

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This part of the monograph addresses the work of the *K'e Project*. In addition to providing background information concerning the *K'e Project* history, organization, and philosophy, the following pages describe how contextual factors within the Navajo Nation impact the work of the *K'e Project*. Finally, we identify concrete contributions the *K'e Project* has made and continues to make to family-provider collaboration and the delivery of family-centered mental health services.

## **Historical, Organizational, and Contextual Background of the K'e Project**

The *K'e Project* came into existence at a time when children's mental health advocates within the Navajo Nation were evaluating existing systems of care (or the lack of them) and the ways in which they had served children and families. The *K'e Project* has few "built-in" or previously-established links between state and county agencies and their own services; as all tribal nations in this country with sovereign status, tribal government and tribal social services are independent of city, county, state, and federal agencies. Further, while Navajo children may be eligible for state funds, state requirements and



expectations often exclude or conflict with components of systems of care developed to serve Navajo children and their families. All of these concerns are central to the ways in which the *K'e Project* delivers services, and to family participation in systems of care.

## **History of the *K'e Project***

The *K'e Project* offers services based on traditional Navajo concepts of healing and wholeness. On the Navajo Nation, traditional Navajo concepts of care exist alongside models of care based on realities and norms from outside of the Navajo traditional way of life. Services based on non-Navajo models of family and healing were (and continue to be) often categorical, and have too frequently emphasized physical health while neglecting mental and behavioral health. The *K'e Project* developed as it became more and more clear that non-Navajo approaches to serving children and families were not adequately responding to the needs of the Navajo people.

In the last 25 to 30 years, social service agencies on the Navajo Nation have increasingly employed Navajos. Particularly in the 1980s, agencies within the Navajo Nation moved toward a multidisciplinary perspective, realizing the value and benefits of agencies working with each other rather than isolated from each other. In the late 1980s, Navajos began to look at the role of traditional healing perspectives in responding to behavioral health issues, particularly with issues including substance abuse. Prior to this, social service agencies rarely, if ever, drew on cultural values or practices that were centered in Navajo knowledge and ways of life.

As the Navajo people looked more closely at the connection between the well-being of their community and the role and importance of values and cultural assumptions in the delivery of services, many agencies began to return to the concept of *K'e* as a foundational component of Navajo well-being. At this time, the Navajo Community Advocacy Committee (previously named Child Protection Team), which currently includes 32 agencies, saw the potential value of a Center for Mental Health Services grant to the Navajo Nation. Further, it became clear to the Navajo Community Advocacy Committee that the current philosophy most of the child-serving agencies were using was not providing services with positive outcomes.

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*As the Navajo people looked more closely at the connection between the well-being of their community and the role and importance of values and cultural assumptions in the delivery of services, many agencies began to return to the concept of *K'e* as a foundational component of Navajo well-being.*

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Central to the *K'e Project* throughout its existence (and beginning with the grant proposal) has been the “sheep camp” philosophy, a concept familiar to the Navajo people and one that begins with “serving people where they are.” Currently, the *K'e Project* uses the “sheep camp” philosophy to provide home-

based services coordinated by six offices. The *K'e Project* is at the beginning of its fifth year of the grant. The *K'e Project* continues to work closely with other agencies; at the same time, it is the only children's mental health agency on the Navajo Nation that offers traditional healing ceremonies as a central component of services.

## **Organization and Services Offered**

With a total of 40 staff, the project provides services that include intensive home-based therapeutic intervention, traditional/cultural counseling and healing, behavior management services, case management, prevention, and outreach and community education. In addition to the staff, there is a 10-member board, which includes 7 family members and consumers of *K'e Project* services. The project is a private, non-profit organization accountable to the Navajo Nation Council's 10-member Health and Social Services Committee, one of several committees of the tribal council. (The Navajo Nation Council is an 88-member council that governs the Navajo Nation.)

Of the six site offices, each administers services through intervention teams, which are made up of one or two therapists; a traditional behavior management specialist; a family support specialist, a case manager; and an administrative liaison. The traditional behavior management specialist offers resources and expertise in traditional Navajo healing approaches. Caseloads, which average 15-30 per site, are in part specified by state regulations. Following referral and the decision to work with a child and his or her family, the family support specialist makes initial contact with the family and child to complete the intake process. At this point, the therapist and the traditional behavior management specialist complete the clinical and family-cultural assessments with the child and family.

After the intake and assessment processes are completed, the case manager initiates a meeting with the child, significant family and clan members, and other relevant agencies (which have been identified during intake). At this team

meeting, the Individualized Service Plan is developed, and then signed by the child and family, the case manager, a school representative, and other relevant agencies (which may include the Navajo Department of Education and Training, a job skills development agency; Navajo Social Services for Protective Services; and the Navajo Prosecutor's Office, which encompasses Juvenile Justice concerns). Finally, a multi-disciplinary treatment

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### ***K'e Project* Organization**

- Offers services to the Navajo Nation, a self-governing entity.
  - Ten-member board includes seven family members and consumers of the *K'e Project* services.
  - Accountable to the Navajo Nation's 10-member Health and Social Services Committee.
  - Forty staff work out of six site offices.
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plan is developed by the therapist, the traditional behavior management specialist, and the family support specialist. *K'e Project* staff use the individualized service plan to address the child's and family's situation in the areas of housing, employment, health care, transportation, and additional socio-economic factors impacting the child's mental health. The multi-disciplinary treatment plan is directed particularly to the child's and family's mental health needs. The delivery of services is home-based; at least two members of the intervention team visit the child's home at least once a week and in some cases more frequently.

## **Context in which the *K'e Project* Provides Services**

The *K'e Project* provides services in a unique setting. Factors including a rural population, the significant number of families who communicate in the Navajo language, a range of socio-economic stressors, the self-governing status of the Navajo Nation, and the development and existence of mental health services within the Navajo Nation, are all crucial to how the *K'e Project* articulates its mission and delivers services.

The Navajo Nation is located at the "four corners" area in the states of Utah, New Mexico, and Arizona. While many people live in small towns on the Nation such as Shiprock, Chinle, and Tuba City, significant numbers of families live on land anywhere from 30 to 75 miles from the nearest town; in some areas, phone service is not available. The size of the nation and the rural nature of the population indicate the time and administrative commitment of the project to home-based care.

Many support structures that are often prevalent in urban and small city/county areas are lacking on the Navajo

Nation. For example, the bus system that does run on the Navajo Nation is not adequate for the needs of the families of the *K'e Project*. Primary health care providers, such as dentists, optometrists, and pharmacists, are often not available. Navajo traditional healing experts rarely fit into the requirements managed care systems have established for reimbursement. Working with three different states requires the *K'e Project* to establish three ways of meeting eligibility and funding requirements, which in turn necessitates knowledge and awareness of the intricacies of each state's mental health system.

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### **Geographic Setting of the *K'e Project***

- Offers services in three states.
  - Navajo Nation is 17 million acres, approximately the same size as Rhode Island, Connecticut, New Jersey, and New Hampshire combined.
  - Many families live 30-75 miles from the nearest town.
  - Phone service is not available in all areas of the Navajo Nation.
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The extent to which families speak the Navajo language in the home and as a preferred language of communication is by no means uniform across the Navajo Nation. According to 1990 census figures, approximately two-thirds of Navajo families speak Navajo at home. Intervention teams must be able to communicate in Navajo.

Because languages carry cultural assumptions and philosophies with them, and because direct translation from English to Navajo is difficult if not impossible, *K'e Project* staff does considerable work translating from English to Navajo, and often back into English again. For example, project staff have taken an assessment form, originally published in English, translated it into Navajo (making it culturally relevant and appropriate), and then translated it back into English to insure validity of the assessment form in a Navajo context. The second English version is never the same as the English version of the form with which the project began.

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*The Navajo Nation is a sovereign, self-governing Nation within the United States.*

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The Navajo people have survived in this country, despite repeated attacks on their land and people, broken treaties, the dividing of families into boarding schools and residential homes, and ongoing socio-economic struggles. Their survival is due largely to their creativity, survival skills, and knowledge of their culture and traditions. The *K'e Project* works with families in an area that experiences high unemployment rates; more than 50 percent of the population falls below the poverty line. Many homes lack complete plumbing and are without access to a vehicle. There are high rates of substance abuse, domestic violence, sexual abuse, and physical abuse among the families the *K'e Project* serves. The experience of separation from families and cultures, which many Navajo people endured through time spent at boarding schools, continues to impact many parents of children receiving services.

Language, living situation, the extent of mental health services on the Navajo Nation, and a variety of socio-economic realities impact the children and families the *K'e Project* serves. Because the well-being and balance of the family is a central component of the *K'e Project* mission, goals and method of service delivery, intervention teams must be particularly aware of how families are working with a range of factors. Services to children and families must address a variety of contextual realities impacting children's mental health.

## ***K'e Philosophy***

The Center for Mental Health Services grant proposal was in large part a response to the growing interest in establishing traditional services for children and their families on the Navajo Nation. Because the concept of *K'e* is central to Navajo life, this philosophy is prevalent throughout families on the Nation.

Nearly all families are at some level familiar with the *K'e* concept; many families understand *K'e* as central to their lives and choices. *K'e* philosophy is not an aspect, component, or result of the project's work; rather, *K'e*, with its attending philosophy and values, is the place from which all of the project's work begins.

The Center for Mental Health Services grant offered a particularly strong opportunity for the initiators of the *K'e Project* to develop services based on *K'e* philosophy and values. Most of the staff of the *K'e Project* are Navajo. Even when Navajo staff have been categorically trained, they have an ongoing sense of the approach to service *K'e* supports. Two key components of *K'e* philosophy and values are the centrality of family, and the clan system. Because the idea of family relates directly to the Navajo understanding of clans, the two concepts do not exist separate from each other. (Although one might look at the family-clan concept in the same way as the connection between the nuclear family and extended family, this comparison misrepresents the Navajo understanding of family and clan.) The complex clan structure in Navajo traditional culture is the foundational framework from which the family emerges.

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***K'e** philosophy is not an aspect, component, or result of the project's work; rather, *K'e*, with its attending philosophy and values, is the place from which all of the project's work begins.*

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In providing services, the *K'e Project* understands the role of the family as central to the well-being of a child. A child reaches balance in part through his or her relationship to the family. This philosophy supporting the role of the family in relationship to the well-being of the child leaves little if any room for the basic tenets of the dominant culture's mental health model. In contrast to most other child-serving agencies

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*In contrast to most other child-serving agencies and children's systems of care, the *K'e Project* has developed within a value system that begins with the connection between a child's well-being and his or her relationship to the family.*

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and children's systems of care, the *K'e Project* has developed within a value system that begins with the connection between a child's well-being and his or her relationship to the family.

As stated previously, the *K'e* concept of family is directly linked to the broader clan structure. In my conversations with intervention teams at two *K'e Project* offices, staff people made clear that families served overwhelmingly refer to clan to talk about family. The clan structure in Navajo culture is complex and has many levels.

The first and most basic level involves an individual and four of his or her relatives. In relation to an individual, his or her first clan is his or her mother's clan, the second clan is his or her father's clan, the third clan is the individual's maternal grandfather's clan, and the fourth clan is his or her

paternal grandfather's clan. Within the Navajo Nation, different clans are tied to different geographical areas and have different histories. For *K'e Project* staff, knowledge of a child's clan is an immediate set of reference points for how that child's identity has been shaped.

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## **The Importance of Clan Relationships to the K'e Project**

### ***As told by staff at the Dilkon site office***

A clan connection can ease the situation when we begin working with a family. In one home, I was related to a boy through our common clan background. We had a grandfather-grandson connection. I kept reminding him of this, making clear our clan relationship from the beginning. For a long while, it was hard to work with this boy; we were not having many results. I kept relating to him on a grandfather and grandson basis. Towards the end of several visits, the boy began to recognize and trust the clan relationship. The team was able to work with the boy, building on his trust of the clan relationship.

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Services thus often become relevant for a child and his or her family in relation to the child's clan framework. Traditions, ceremonies, and social expectations and mores are always connected to a child's clan background. The clan structure also establishes family relationships based on common clan ancestry. Thus, relationship is not determined by biological parents alone. When a child shares clan background with a therapist or family support specialist, recognition of shared clan background by the child and the *K'e Project* staff person establishes a familial relationship between the child, the child's parents, and the intervention team members offering services.

Within Navajo tradition and life, clan structures and relationships have tremendous significance, and similarly have a profound impact on delivery of services. Shared clanship between a parent and child, and a member of the intervention team, can immediately result in a shared frame of reference and in a level of trust from which to offer support and services to the family and child. Clanship can lend a sense of guidance to the family, child, and intervention team. Further, as clanship shapes identity and draws on particular traditions and strengths, establishing the child and family's clan becomes an accepted and familiar way of providing strength-based services. Because the Navajo understand people with common clanship to be relatives, the *K'e* system of clanship becomes an appropriate and common way to ask for support. In short, through shared clan background, families have a process to request services that is meaningful and respectful of their role as parents.

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*When a child shares clan background with a therapist or family support specialist, recognition of shared clan background by the child and the K'e Project staff person establishes a familial relationship between the child, the child's parents, and the intervention team members offering services.*

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The *K'e* philosophy and values, in relation to the clanship system, drive the *K'e Project* and the delivery of services the project offers. The prevalence of *K'e* philosophy among the people the *K'e Project* serves, as well as the significance of *K'e* to the project itself, offer a unique model of a system of care, as well as unique contributions to the issue of family-provider collaboration. The remainder of this section addresses particular contributions the *K'e Project* makes to the process of family-provider collaboration.

## **The *K'e Project* and Family-Provider Collaboration**

Navajo approaches to healing begin within the context and physical expression of family; children's mental health needs are understood entirely within the setting of family and clan, and are not separable from this setting. In Navajo culture, when healing for a child is necessary, a healer enters into the setting of the family and responds to the needs and wants articulated by that family and child. In a traditional Navajo context, then, delivery of services for a child begins, in a very immediate and physical sense, where the family is.

The concept of family-provider collaboration has particular relevance and makes the most sense in a context where healing for children begins from outside of the family context, and where delivery of services to children is detached from the context of family (in obvious or subtle ways). The concept of collaboration has meaning only if and when there has been a break or a separation among participants involved in the process of caring for a child. Family-provider collaboration in children's mental health has become a goal for many participants in systems of care within a context in which the medical model has been the predominant response to a child experiencing mental, behavioral, or emotional disorders. In part because the medical model blamed, disrespected, and devalued families at nearly every level in systems of care, the concept and practice of collaboration has become an important objective for participants in systems of care who view families as a vital component of the child's well-being.

Staff at the *K'e Project* deliver services to children and families in a Navajo context that has valued and continues to value families in the process of caring for children with emotional, mental, or behavioral disorders. These services do not emerge out of a medical model. *K'e Project* intervention teams represent a wealth of training and expertise in the areas of healing and children's mental health. Navajo traditional healing methods and knowledge, as well as theories and methods taught in social work and counseling programs, inform the work of the *K'e Project*. Because of the project's emphasis on *K'e* philosophy and values in regards to the delivery of services, *K'e Project* staff must be particularly attentive to the nuances

and assumptions that exist within Western models of care taught in universities. While much of the training in social work and counseling is of value for the *K'e Project*, lingering acceptance of the medical model in

some universities contradicts the values and goals of the work the project does on the Navajo Nation.

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*In a traditional Navajo context, delivery of services for a child begins, in a very immediate and physical sense, where the family is.*

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The *K'e Project* offers insight into the process of family-provider collaboration in large part due to its basis in a Navajo understanding of care and well-being. For participants in systems

of care working toward collaboration, the *K'e Project* is unique in that it begins with a model of care and service delivery that has consistently understood the primacy of the family to a child's well-being and the relevance of people with expertise in healing to children's mental health. The *K'e Project's* commitment to the following three aspects of their work in children's mental health have particular relevance to participants in systems of care working toward collaboration:

- the importance of understanding development and delivery of services as a process;
- the focus on a system of care that is community-based and culturally competent; and
- the centrality and value of family to the project.

## **Commitment to a Process**

Through conversations with Cecilia Belone, project director, and following site visits to the *K'e Project* and two offices, it became clear that the importance of understanding the work of the project as a process is widespread among project staff members. Commitment to a process requires considerable time and energy, a willingness to rethink ideas and beliefs, an ability to change, and the vulnerability demanded when taking risks. While it is often more expedient and less time-consuming for children's mental health sites to resist change and constant reevaluation, a staff's commitment to service delivery as a process leaves considerable room for critique and adjustment of services. The *K'e Project* understands the value of a process-based approach at the levels of goals and mission, delivery of services, and staff development.

The earliest commitment to a process at the project level came for the *K'e Project* in the initial writing of the grant. The people interested in the development of a home-based system of care built on Navajo tradition and culture knew the work would be difficult and would require constant reevaluation and growth. When articulating the goals and objectives of the project, the *K'e Project* Board of Directors begins by reevaluating the mission statement, and follows up with addressing how the funding sources can support the objectives of the mission statement (rather than letting funding determine the parameters of the project's mission). At the same time, the staff and board must constantly ask, "Are these realistic



expectations?" A final emphasis on process at the project level is in the area of decision making. The *K'e Project* uses a consensus model to make decisions. Consensus enables a range of voices and opinions to be present when staff are making decisions about services; flexibility and the priorities of families are more likely to be valued through consensus than through a decision making framework that rests on the position one holds or a "majority rules" model.

*K'e Project* staff also understands the delivery of services as a process, the first step of which is to establish a relationship with the child and his or her family. At least two members of the intervention team visit the home once a week and in some cases more frequently. This regular contact occurs even when not all members of the family will be at the home. Thus, visits from the *K'e Project* become part of the family's weekly rhythm. For *K'e Project* staff, home visits require close and ongoing attention to the family's situation, which is often itself changing. In addition to gauging the family's reality each visit, staff must work at bridging the family's and child's concerns with ceremonies appropriate to the family and clan.

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*The K'e Project understands the value of a process-based approach at the levels of goals and mission, delivery of services, and staff development.*

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Consensus also has significance at the level of delivery of services. Because *K'e Project* intervention teams are frequently in the home with families, and because consensus is a widely-accepted decision-making method among Navajo people, staff and families become equally important when making decisions concerning a child and his or her treatment plan. In short, because *K'e Project* staff are

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*The K'e Project uses a consensus model to make decisions. Consensus enables a range of voices and opinions to be present when staff are making decisions about services.*

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constantly in contact with the family and the child, staff have found it critically important to be sensitive to and respectful of changes at the home and within the family, an approach that requires attentiveness and flexibility.

At the level of staff development, there is a commitment to process particularly in the area of reeducation of staff. Despite the prevalence of *K'e* philosophy and values among Navajo people, assumptions tied to the medical model of care continue to surface. Staff must remind each other that children are served within the context of family, and that it is inappropriate in a Navajo context to separate emotional, behavioral, mental, spiritual, and physical components of health and well-being. Reeducation often occurs slowly; offering guidance demands sensitivity and patience.

Commitment to a process, rather than an insistence on fixed approaches to care and delivery of services, requires, as the project director at the *K'e Project* states, a "commitment not just to a job but to a set of values." Further, understanding delivery of services as a process in which families have a central role

directly impacts the staff. As one therapist commented in speaking of home visits and family participation in the child's care, "You wear all that." Finally, as the *K'e Project* site director comments, commitment to delivery of services as a process will encounter resistance; valuing process requires consistency, continuity, supervision, and frequent reevaluation of the project's goals and priorities.

## **A Community-Based and Culturally Competent System of Care**

The *K'e Project* has been particularly invested in families' priorities and expectations as related to delivery of services. When the *K'e Project* began, families on the Navajo Nation were explicitly asking for Navajo-based services. Additional ways in which the *K'e Project* respects and values the community with which they are working include staff's recognition of the significance of the services offered in the Navajo language, and the concern for differences among families.

For many of the Navajo people, language establishes self-identity and serves as a way to recognize and know reality. Delivering services in the Navajo language, then, becomes profoundly significant and one way of validating the family as central to the child's care. Particularly in a context in which many parents have been punished for using their language, offering services in Navajo can be immediately collaborative. Addressing and articulating the family's situation in Navajo terms resists oversimplification and better holds the complexity of the realities with which the family is living. Using the Navajo language indicates a valuing of Navajo culture and life, which in turn becomes a way of identifying strengths the family has established in caring for their child.

Culturally competent care also requires a recognition of differences among Navajo families. In the process of assessment, families identify their familiarity with and preference for particular approaches to care (Navajo, Western, and Christian are three models relevant to the Navajo Nation). Further, within Navajo traditional methods, there are several variations. Different families are familiar with different ceremonies; families have varying levels of comfort with Navajo traditional methods. In connection with clan background and context, staff must be aware of clan history and current realities; questions such as "What is occurring?" "Why?" "What is the link to clan background?" and "How will this impact children?" all become questions central to a community-based and culturally competent system of care.

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***F**or many of the Navajo people, language establishes self-identity and serves as a way to recognize and know reality.*

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Intricate attention to language and cultural norms on the part of *K'e Project* staff establishes a profound level of respect and concern for the centrality of families to their children's health and well-being. Knowledge of language and cultural norms confirms to families that they are part of a healing process rather than an addition to their child's care.

## **The Centrality of Family in K'e Philosophy and Values**

*K'e* philosophy is built on the worth of the family and clan to individual and society well-being. This understanding of health and wholeness is profoundly different from the medical model and has significant implications when offering children's mental health services. Although many *K'e Project* staff have been trained to work categorically, Navajo staff have a sense of what a holistic approach requires. *K'e Project* staff begin services with a recognition of the family's current plan for healing and treatment. Rather than imposing a treatment plan on the child and family, *K'e Project* staff work with the family and support the family's choices as those choices further the child's healing.

Home-based delivery of services within a system of care that has come out of a medical model (even if that system of care is in certain ways in opposition to a medical model) is likely, to some extent, to rely on a medical model's understanding of family. Home-based delivery of services within the *K'e Project* emerges out of a philosophy and set of values that knows the family as central to a child's well-being. In this context, family members and the *K'e Project* staff together work toward a child's healing. Home-based care enables listening to happen in the environment in that the family is most familiar, supports a closeness to stressors that are impacting children, and allows the development of relationships in a setting which is central to the family.

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***R**ather than imposing a treatment plan on the child and family, *K'e Project* staff work with the family and support the family's choices as those choices further the child's healing.*

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The *K'e Project* is unique because of the significance of *K'e* philosophy to its mission and goals. Even as the dominant culture has imposed services and stressors on the Navajo community (including services based on a medical model), the Navajo people have always had a culturally-based value system on which to draw. *K'e* philosophy is an established and successful set of beliefs, as well as a set of values, social assumptions and expectations which the Navajo people hold in common. *K'e* is a way of living and a way of caring for children that has ensured the survival of the Navajo people and culture. In short, through *K'e*, "a reverence for all things in the universe" and children's "central process for healing," the Navajo people have

always known that acting as if providers are more important than families in a child's healing process does active disservice to the child and family, and ultimately to the community and society. The *K'e Project* knows family and healers as equally necessary for a child's well-being.

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### **Working with the Family in the Home: An Example *As described by staff at the Gallup site office***

Offering services on a regular basis in the home helps us understand what the family is going through and what kind of support will be helpful. In one family, a girl was referred to us. After a few visits to her home and through talking with the family, we could see that the girl was doing okay. She had developed successful strategies to deal with her life and situation. After a couple visits, we noticed her younger sister was having some problems. We began working with the younger sister and that improved the situation for the entire family. By visiting the family on a regular basis, listening to them and being with them in their home, we were able to identify the sibling, offer support, and build on the strengths of the entire family.

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## **Conclusion**

The *K'e Project* is approaching the end of its five-year grant. In a short four years, *K'e Project* staff and board members have built a system of care and established a range of services for children and families. They have accomplished this in a context where all families are impacted by socio-economic and life stressors. The *K'e Project* offers services based on Navajo philosophy and values; there is little precedent for this within a social services or mental health context. Finally, they have designed and implemented their mission statement and goals in ways that understand families as central to healing children who have emotional, behavioral, and mental health needs.

The Children's Mental Health Services grant has provided a rare and significant opportunity for *K'e Project* staff and board members to provide community-based, culturally competent, and non-categorical services to the Navajo Nation. As the *K'e Project* works toward future funding, the almost complete lack of funds that support wraparound, non-categorical services on the Navajo Nation is a major challenge. The *K'e Project* has become an integral component of the Navajo Nation, and the only children's mental health service provider that offers services centered in Navajo tradition

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*The Navajo people have always known that acting as if providers are more important than families in a child's healing process does active disservice to the child and family, and ultimately to the community and society.*

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and culture. The opportunity that the Center for Mental Health Services grant provided, then, runs the risk of becoming a particularly poignant irony: there is little (if any) local and state support for the services the *K'e Project* is providing.

As *K'e Project* staff and board members work at implementing services that are based on *K'e* philosophy, one lesson in particular has become painfully clear. While it is possible to incorporate Western (non-Navajo) values and concepts into Navajo mental health systems of care, it is not possible to incorporate Navajo culture and beliefs into a Western mental health system of care and retain Navajo culture and beliefs. In cases where social services providers have tried to shape Navajo concepts into a Western framework, the concepts lose their connection to a Navajo belief system and world view. As Cecilia Belone states, the only way to fit a square peg into a round hole is to change the square peg until it is no longer square, but round.

The *K'e Project* offers insight into family-provider collaboration precisely because family-centered healing is central to *K'e* philosophy. The *K'e Project's* contributions to family-provider collaboration become the most useful when those contributions are understood within a Navajo context. The *K'e Project* offers insight into family-provider collaboration because *K'e* philosophy and the Navajo people have resisted the separation between families and providers that makes collaboration necessary in the first place. It is in the intricacies of that resistance, and in the core concepts of *K'e* philosophy and values, where the components of collaboration can be found.

## **SONOMA-NAPA COUNTY COMPREHENSIVE SYSTEM OF CARE**

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### **Napa and Sonoma Counties, California: An Overview**

#### **APPROACH**

- Mutual education and support through hiring family members into the system of care.
- Ensuring family input through contracting with family organization.

#### **PROMISING PRACTICES**

Increasing integration of family members at all levels of system of care, through:

- Family/Professional Partnership Plan
  - Families participation in evaluation of services
  - Broad array of family support services
  - Families working in key roles in system of care
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The *Sonoma-Napa County Comprehensive System of Care (SNCSC)* is a two-county collaboration funded by the Center for Mental Health Services in 1994. The overall goal of the *SNCSC* is to develop systems and methods of service to maintain children with serious emotional disturbances in their homes, or in the least-restrictive, most-homelike setting that is therapeutically possible. Although each county operates its own service system, the two counties work together through joint planning, training, evaluation, and by sharing other resources.

Napa County is a relatively small county (population 110,000) that has a strong sense of community, and a history of interagency collaboration, especially in relation to children for whom residential care has been recommended. An interagency group, Multi-Agency Residential Planning, or MARP, meets weekly to plan for these children. A county-level Health and Human Services agency serves as the umbrella agency for health and social services, and it is within this agency that the system of care initiative is located. Representatives from Matrix, a Parent Network and Resource Center and an established family advocacy and support organization that serves families whose children have a variety of disabilities, were involved in the planning process that lead up to the grant application to the Center for Mental Health Services.

Sonoma County (population 500,000) also involved representatives of local family organizations during 1993, the planning year for the Comprehensive System of Care. At that time there were several local family organizations operating: Children and Adults with Attention Deficit Hyperactivity Disorders, serving persons

with Attention Deficit Disorder; Matrix, an educationally-oriented family organization that serves all disabilities; and the Sonoma County Alliance for the Mentally Ill, which focused primarily on adults with severe and persistent mental illness. All had an interest in promoting better services for these families, even though none of the three organizations had an exclusive focus on families whose children had emotional, behavioral, or mental disorders. In order to promote close working relationships between parents and staff, the leadership decided that it was important to have “inside parents,” family members who worked within the system. A decision was made to work with a coalition of existing local family organizations, and to invest energy and resources in achieving family integration and involvement at all levels of the system, from within the system. This strategy will be discussed in greater detail below.

The Sonoma-Napa System of Care is examined here with an emphasis on two challenges related to family-professional relationships, although other aspects of collaboration are also addressed:

- *Existence and tolerance of tokenism related to family participation.* The promising practices that we examine in Napa and Sonoma Counties related to this challenge revolve around the strategies used to increase access and integration of family members into all levels of the system of care.
- *Achieving sustainability of the family organization following the grant.* Because the Sonoma-Napa System of Care chose to focus on integrating families into the system of care at all levels, rather than starting a new family organization, the emphasis here is on sustainability of family participation and partnership, rather than on a family organization, per se. The benefits and possible shortcomings of this approach are discussed, with a view to providing information that other communities can consider when making decisions.

*Strategies to Increase Integration of Family Members into All Levels of the System of Care.* Both Napa and Sonoma counties elected to focus resources on integrating family members into the formal system of care, rather than on starting or supporting a new family organization focused exclusively on families whose children have mental health problems. In the following discussion, we focus first on strategies and actions taken by both counties, and then on issues unique to each county.

Common or similar initiatives in Napa and Sonoma counties include:

- developing and implementing a formal Family/Professional Partnership Development Plan that outlines action steps to achieve partnership in administrative, policy, and service delivery arenas;
- placing family members in key roles within the service delivery system, with explicit attention to involvement at all levels;

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*Napa County has a strong sense of community, and a history of interagency collaboration, especially in relation to children for whom residential care has been recommended.*

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- commissioning an evaluation of services from the perspectives of family members, with commitment to using the results to improve the system of care; and
- making available a broad array of family support services, including family support groups, parent-to-parent mentoring, educational and training opportunities, resource libraries, and explicit family leadership development.

## **Family Partnership Initiative**

All seven Center for Mental Health Services sites in California have adopted a framework for a Family/Professional Partnership Development Plan. This plan is a formal policy document developed by families and system of care administrative personnel and other staff.

The term “development” within the title of the plan underlines a central premise of the effort, that is, that family-professional partnership is a goal that involves an ongoing process and that requires serious attention to make and maintain progress. Each of the seven California sites worked with the common framework, and adapted the Family/Professional Partnership Development Plan to fit local capacities and circumstances. Napa and Sonoma counties engaged in similar processes to tailor the plan to the unique circumstances of each county, and Sonoma County’s adaptations are codified in a formal document. The mission statement in Sonoma County’s Family/Professional Partnership Development Plan reads:

*It is the mission of the Sonoma County Youth and Family Services System of Care to involve parents and families of children and youth with serious emotional disturbance as full partners in every aspect of the system of care.*

The document outlines a plan to achieve full family participation in the administrative, policy, and service delivery arenas, and identifies concrete action steps that should be taken to develop and maintain a working partnership including both structural and process steps. Highlights from the plan include:

- A committee of staff, contract providers, and families was established to track and evaluate the implementation of the family/professional partnership plan. It is hoped that this committee will soon become a permanent sub-committee of the Mental Health Board.
- Staff and family training are promoted to increase competence in family-centered service provision and understanding of system of care issues.
- Families are included in:
  - all levels of policy making
  - the grievance structure
  - evaluation of the organization and of services

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*A decision was made to work with a coalition of existing local family organizations, and to invest energy and resources in achieving family integration and involvement at all levels from within the system.*

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- human resource development activities including recruitment and hiring
- Policy and procedures manuals must be examined to be sure that they incorporate family/professional collaboration activities.
- Family/professional partnership principles are included in contracts with community-based organizations.
- Family involvement must be ensured in the contracting process.
- Job descriptions and performance expectations for staff are reviewed and revised to ensure that they reflect family/professional partnership advocacy principles.

Family Partners are a key part of policy making and oversight with regard to the network of agency partners in the system of care in several ways, including membership on an interagency contract oversight committee that meets monthly; participation in the annual contract review process, which involves assessment of the year's work; and planning and decision making for the coming year. Acceptance of the concept of full family partnership is still only partial, but some progress is evident in a recent requirement that the Juvenile Justice Probation Advisory committee have at least one family member and one youth as members. Appreciation of the contribution of family perspectives is also apparent in a request from the Education Screening Committee (a joint mental health/special education body) for family review of its procedures. Job description and performance expectations that new staff have the ability to develop partnerships are also bolstered by the participation of Family Partners on all hiring panels, and at each of three levels of the county's personnel process.

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*It is the mission of the Sonoma County Youth and Family Services System of Care to involve parents and families of children and youth with serious emotional disturbance as full partners in every aspect of the system of care.*

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## **Placing Family Members in Key Roles within the System of Care**

In Napa County, the organizations applying for the Center for Mental Health Services grant chose to work with an established parent advocacy group, Matrix, which is an educationally-oriented cross-disability family organization that serves four California counties. The SOC contracted with Matrix for the part-time services of Joan Lockhart, who had many years of experience doing advocacy for families in Napa County, and could build on existing relationships with individuals and organizations in the community. Through her work with Matrix, Ms. Lockhart had existing relationships with other child-serving systems such as the Juvenile Justice department and the schools. Her charge was to review the extent that services were family friendly and family-centered through attending staff meetings in the department of Health and Human Services, reviewing memoranda of understanding with schools and other agencies, visiting with supervisors to discuss ways to increase the degree to which families were included in the system, and other similar activities. Staff in the Napa

County mental health agency were told that when Ms. Lockhart came to meetings, “she should be treated like staff.” Ms. Lockhart was given open access to all staff and interagency meetings. Not surprisingly, the site supervisor, Beth Craigie, and the family advocate, Ms. Lockhart, initially had different perspectives on the role that Ms. Lockhart and Matrix, were to play. Beth Craigie had a vision of family members as system advisors (i.e., emphasizing benefits to the system), and Ms. Lockhart, the family advocate, saw her access to the system of care as supportive to existing family efforts (focusing on benefits to families).

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*Job description and performance expectations that new staff have the ability to develop partnerships are also bolstered by the participation of Family Partners on all hiring panels, and at each of three levels of the county's personnel process.*

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One of the first activities that Ms. Lockhart, the parent advocate, undertook was to organize a Family Advisory Committee for the system of care. This group consists of a core group of about 10 family members, with a number of others involved as they are able. From the beginning, the Family Advisory Group included the site supervisor, Beth Craigie, as a staff member in all meetings. Subsequently, other staff were invited to some meetings for specific reasons. The group helped form ideas about how the system of care could be refined and improved, and right away, wanted some power to help make changes. A mechanism called the “Parent Door” was established, which serves as a point of access and referral for families seeking help. The Parent Door helps families new to the system find what they need, and also works with families who are having problems accessing needed services (i.e., who have been turned down for services). The Parent Door is a service staffed by both paid and volunteer family members in Napa County.

One structural change that increased visibility of commitment to family participation and

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*A training event organized by Napa County Health and Human Services was a critical turning point supporting family participation in the system of care.*

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collaboration was a revamping of the case conference. Initially, case conferences were clinically-based and largely attended by professionals (including staff and supervisors). Through several meetings, the case conference was changed so that it was no longer clinically-based; family members were there; the approach was strength-based; and the family members' perspectives were central to the outcome of the conference.

The Napa County Director of Health and Human Services, Terry Longoria, sent out personal invitations for a wraparound training to a variety of agencies. Several national trainers were present, and many management staff and supervisors from a wide variety of agencies attended, as well as representatives

from several non-profit organizations. This training resulted in a collaborative that met on a monthly basis for a year, as well as an executive committee at the county level. Both the collaborative and the executive committee had strong family participation.

Despite a clear mandate that family participation was an expected part of doing business, a number of mental health staff were concerned about the family advocate coming to staff meetings. The general strategy employed by the site supervisor was to nod, listen, and then say, "We're going to do it anyway."

At first, participants in interagency meetings were also cautious about having a parent present. Now, however, system of care partner agencies in Napa County are beginning to see advantages to having family members as part of the team. For example, in times of crisis, it is much easier to connect and work with families when parent advocates have a connection and a relationship. In the schools, the connections that Ms. Lockhart has (e.g., with supervisors in special education) help to pave the way for others. Ms. Lockhart and other family members also work with supervisors in the child welfare and probation systems.

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*The Parent Door helps families new to the system find what they need, and also works with families who are having problems accessing needed services (i.e., who have been turned down for services).*

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*One structural change that increased visibility of commitment to family participation and collaboration was a revamping of the case conference. The format was changed to make it much more family focused, and to insure that both families and community agencies were active participants.*

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During subsequent years of the grant, the amount of funds available for family efforts was increased. Two additional family members were hired in the system of care as Parent Advocates (total for three family contract staff of 2.0 FTE). All family members are contracted through Matrix. Contracting is seen by family members as the preferred relationship between the family organization and the system of care because it affords more flexibility, and does not compromise the organization's ability to engage in advocacy. The system also provides about \$4,000 for parent stipends, which can be used to reimburse family members for expenses, and also pay them for the time they

spend serving in a variety of capacities—from attending advisory or interagency meetings, to providing support for other families, including training and transportation.

In Napa County, family members are a part of the hiring processes for mental health, serve as members of interdisciplinary teams, and attend staff meetings. Family members have also taken increasing responsibility for Family Team Meetings, which are wraparound planning meetings held in families' homes or other locations of their choice. Initially, the Family Team Meetings were organized by the care coordinators (mental health staff) for families. Currently, a parent advocate is employed to set up these meetings; parent

advocates often facilitate at the meetings. Several family support group meetings are held each month in Napa County, and there is also an extensive system of parent-to-parent telephone contact and support ("Parent Partners"). Additionally, parents serve on the Juvenile Justice Commission and Mental Health Association.

In Sonoma County there are currently eight family members employed by the system of care. These include a full-time Family Advocate, Dawn Hensley, and seven Family Partners who together occupy 5.0 FTE. The family advocate position was designed as a permanent position within the county structure from its inception. Both Dawn Hensley, the Family Advocate, and Marjorie Helm, the Sonoma County Mental Health Director, identify the degree of access and integration of family members within the system of care as "revolutionary."

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*A training event organized by Napa County Health and Human Services was a critical turning point supporting family participation in the system of care.*

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The roles and duties of the Family Advocate and Family Partnership Assistants have evolved since the system of care was funded in 1994. Originally, the plan was to have the Family Advocate organize a cadre of family volunteers, but over time it became clear that it was important to add more family members as paid staff members, working "shoulder to shoulder" with professional staff. Extensive family "volunteerism" came to be seen as infeasible and unfair. Recently staff have been organized into five geographic interdisciplinary teams, with one part-time family staff member assigned to each team. There is also a part-time family advocate who works with families in the day treatment program. In the system of care plan for re-design in preparation for managed care, each team will have active participation from family members.

The Family Advocate job responsibilities include:

- to work with others to develop a parent support system that includes, but is not limited to:
  - parent support groups
  - family newsletter
  - Parent Advisory Board
  - Educational forum
- to act as liaison between families and the mental health system;
- to ensure that family members are treated with respect by the mental health system, its representatives, and service providers;
- to serve as a focal point for developing parent participation in treatment, policy making, hiring panels, and other decision-making arenas;

- to develop family education strategies to equip family members with additional competence in dealing with their family members' illness;
- to develop relationships with service providers;
- to conduct outreach to family members of minority children with serious emotional disturbance; and
- to maintain liaison with family support organizations.

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*Both the Family Advocate and the Sonoma County Mental Health Director identify the degree of access and integration of family members within the system of care as "revolutionary."*

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One important role of the Family Advocate is to share responsibility for the training and supervision of the Family Partnership Assistants who are assigned to the interdisciplinary teams. Each team selects and supervises the Family Partnership Assistants; the Family Advocate meets with them in a weekly group, and is responsible for coordinating their activities. Other important family member roles in Sonoma County include: family membership on all hiring panels, family representation in grievance procedures, membership on the Mental Health Board, and membership on the Family/Professional Partnership Group.

## **Family Participation in Evaluation**

Family members and staff alike felt that the "parent satisfaction" information in the national evaluation for the grant program did not provide enough detailed information about their systems to refine and improve the system of care in Sonoma and Napa counties. Consequently, in 1997-98 an outside evaluator, Dr. Mary McCormack, was hired to work with families and staff to design and implement an evaluation that would provide specific information for system and service improvement. Family members, evaluation team staff, and system administrators from Napa and Sonoma counties created the plan for the study. The main purposes of the study were to ascertain what services were helpful to families and how they experienced the system. Dr. McCormack worked with an evaluation team including two family member interviewers to collect, analyze and report the data from 135 interviews. In-depth interviews were conducted with family members, youth, and their care managers around questions of access, "family-friendliness" of services, and service effectiveness. It is anticipated that this evaluation information will be used extensively to refine both the process and content of service delivery. This evaluation is jointly funded by Napa and Sonoma counties, the National Resource Network, and the Research and Training Center on Family Support and Children's Mental Health.

## **Sustainability**

In May, 1998, the Napa County site director, Mary Butler, stated that hiring and keeping parents has been a number one priority since the beginning of the grant. The central sustainability strategy that Napa

County has been pursuing with regard to the family presence within the system is to create a pool of flexible funds through having all System of Care partners contribute. This fund would then pay for family staff members. This goal is supported by staff within the mental health system, who identified “getting healthy parent mentors across systems” as the second priority in a recent future planning process. This commitment was reiterated in September 1998, by the Director of Napa County Health and Human Services, Terry

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Longoria, who said that she would not let the two key elements of the system of care, paid family services, and flexible funding, disappear. Still in question as of September, 1998, are the specific mechanisms for sustaining paid family participation in the system of care after grant funds are gone. A number of strategies have been considered, including use of state-level system of care funding, and grant-writing. Specific strategies to institutionalize paid family services, rather than depending on “soft” (and temporary) funds have yet to be identified.

In Sonoma County, the Family Advocate position has been made a permanent county position. The eight family members who serve as Family Partnership Assistants are hired in one of two existing county classifications. The next step is to obtain permanent county funding for these positions so that they will be secure after the grant funds are gone. Another form of sustainability for family participation is the possibility of family partners’ direct service work funded through MediCal (California’s Medicaid program). It is hoped that the family partners will bill for the time they spend doing direct service and that this can be reimbursed through MediCal.

Current leadership in Sonoma County appears to be very committed to having family members be an ongoing, integrated part of the formal system of care. There is considerable optimism in Sonoma County about the ability to sustain the current emphasis on family partnerships, due, in part to the fact that the County will receive system of care funding from the state. Receipt of this state funding will require a continued emphasis on building partnerships with families, and thus will provide continued impetus for change.

## **Lessons Learned**

At least seven lessons were learned in examining the Napa and Sonoma Counties System of Care. These are highlighted below:

- ***Collaboration is a process that requires concentrated and continuous commitment,*** attention, and effort to build necessary relationships, manage conflict, and maintain focus on goals.

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*In 1997-98 an outside evaluator was hired to work with families and staff to design and implement an evaluation that would provide specific information for system and service improvement.*

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- ***Family members can be successfully integrated into service delivery (on teams, in the system), but this requires much attention to implementation of this innovation.*** A process for adding family members to teams is essential (i.e., can't just "drop a parent" into a team setting). Now, the Family Advocate, Dawn Hensley, and others have developed a "getting to know you" process that involves both staff and family members' reflecting on what it's like to have family members working in the team, with an emphasis on building initial trust that is fundamental to teamwork.
- ***Family members must be paid for their time and effort.*** It is not realistic to expect family members to volunteer on an extensive, long-term basis. Hiring or contracting with family members also gives them peer status and credibility with other paid service providers.
- ***It is important for staff to have daily, "shoulder-to-shoulder" experience with family members.*** The move in Sonoma County to geographic teams was an opportunity to institutionalize assignment of family members to each team. In Napa County, Matrix Parent Advocates are housed in the same space as Care Coordinators, at the Child and Family Behavioral Health Office.
- ***Interagency settings may pose a special challenge for family members in service provision roles.*** Representatives of various agency partners (e.g., child welfare, education, Juvenile Justice) are often cautious, if not resistant; confidentiality and concern about "dual relationships" may be used as reasons why family members should not be included.
- ***Families should not be assigned to teams that are serving their children.*** Families in the *Sonoma-Napa County Comprehensive System of Care* have the option to receive services in another county, but have not yet used this option.
- ***Families working within the system need ongoing training and support.*** At the statewide level, the family coordinators from each of the funded Center for Mental Health Services sites in California meet periodically as the Family Representative Network. This group provides the members with an opportunity to exchange information about how things are going at each of the sites, and is a source of both emotional and tangible support for the members in providing leadership in their communities. Regular training for family members and other staff is also provided.

In addition, a central issue related to the model for family inclusion chosen by Sonoma and Napa counties includes a concern that the commitment to having family members as a part of the system is too dependent on current administrative leadership, and that if that leadership changed, family members might no longer be valued or hired. This possibility is difficult to counter, although Napa County has survived several changes in professional leadership, and appears to have retained a commitment to families. The leadership in Sonoma County has been stable thus far. In Sonoma County, as parents have been integrated into the system, increasing numbers of staff value their participation, and often request it.

Specific to Sonoma County's approach to family inclusion is the concern that family members may be coopted when they work within the system, especially without a strong family organization that focuses

exclusively on families whose children have mental health problems. This concern has to do with the possibility that family members will face conflict when the needs of families and the characteristics of the system that pays their salaries are incompatible. Specifically, family members who are also system employees may feel unable to advocate freely for the families they serve. Both family members and the mental health leadership answer this criticism similarly. They acknowledge the possibility of cooptation, pointing to the positive aspects, meaning that family members and professionals discover similarities and develop empathy for one another. In Sonoma County, they use the term, “mutual cooptation,” saying that having family members within the system helps to heal the system from within.



## **EAST BALTIMORE MENTAL HEALTH PARTNERSHIP**

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### **East Baltimore Mental Health Partnership: An Overview**

#### **APPROACH**

Partner with an established independent family advocacy organization.

#### **PROMISING PRACTICE**

Working together to establish and maintain a family friendly system of care.

- family members involved from inception of Partnership and at all levels
  - family members given responsible roles within the system, treated as equals
  - family advocates work closely with Partnership staff and attend team meetings
  - family advocacy organization has autonomy with regard to most decisions
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### **History and Background**

The *East Baltimore Mental Health Partnership* received Children's Mental Health Initiative funding in September of 1993 and began serving children in 1994. The Partnership is currently in its fifth year and just received an extension for a sixth year to continue participation in the outcome evaluation. The *Partnership* serves a primarily African American population in a large section of East Baltimore. The central entity in the *Partnership* is Johns Hopkins Hospital, which collaborates with other private and public agencies including Juvenile Justice, the Department of Social Services, the Mayor's office and City police. The Partnership provides a full range of mental health services for the children and families. Two components of these services are of special interest to this discussion. The school-based program represents an alliance with 19 Baltimore City Public Schools, through which 3,800 children were seen in 1997. The Family Resource Coordination Unit (FRCU) provides the Partnership's most intensive services, allowing for extensive coordination of services and access to wraparound. The Family Resource Coordination Unit provided services to 240 children and their families in 1997. The family advocates can be involved with any of these families but usually work most with families receiving services within the Family Resource Coordination Unit.

*Families Involved Together (FIT)* was formed in 1991 to provide peer support to families of children with severe emotional disabilities. Originally, FIT was a program of the Family Preservation Initiative of Baltimore City, an Annie E. Casey initiative to help children in out-of-state residential treatment return to their communities. Diane Sakwa, the director of FIT, was the first parent to be hired in 1991 to

work with families for 10 hours each week. Since that time, FIT has evolved to include three projects in addition to the contract with the Partnership. These are: *A Helping Hand*, which presents information about disabilities in middle schools and awards community service credits to youth who volunteer with families and their child with a disability; *CityWide*, a program that trains and coordinates volunteer advocates; and *Parent Education Network (PEN)*, a National Institute for Mental Health (NIMH) study of the efficacy of peer family support. *FIT* currently employs seven full-time staff—all family members of a child with a disability. *FIT* functioned under the fiscal agency of the Family Preservation Initiative for six years before becoming an independent private, non-profit organization in July 1997.

Since the Partnership grant proposal was in the planning stages, the major strategy for involving family members and providing support and advocacy has been through the support of an independent family-run organization. In this strategy, generous resources from the *Partnership* budget are set aside for contracting with *Families Involved Together*. The family advocates are hired and supervised by the *FIT* director and are employees of *FIT*. They work integrally with the *Partnership* staff and have in-depth knowledge of services of the *Partnership*. The goal in this model is to provide an independent advocate that will assure that the service system is accountable to families.

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*Since the grant proposal was in the planning stages, the major strategy for involving family members and providing support and advocacy has been through the support of an independent family-run organization.*

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## **Building Trust and Respect**

The relationship between family advocates and the mental health planners and providers in East Baltimore has been collegial and relatively smooth. From the beginning of the planning process for the system of care grant, the leadership in the persons of Dr. Phil Leaf and his colleagues had a clear understanding of the need to involve family members in the development of the system. They were responsible for convening a group called the Baltimore City Child Resources Task Force to do the original planning. Susan Tager, a family member, was an active participant in this task force and was part of the planning for the proposal. In addition, Phil interviewed advocacy leaders (including the director of *Families Involved Together [FIT]*), and family members in their homes and at support group meetings in order to educate himself about the needs of families. Susan notes that her input and that of a group of families who were interviewed was reflected in the grant.

Once the proposal was funded, Phil brought together the three advocacy organizations that were active at that time, staff and family members from the Baltimore Chapter of the Alliance for the Mentally Ill

(AMI), and *FIT* as well as community members and parents who were receiving services from children's mental health programs at Johns Hopkins Hospital. This group met regularly over a period of months and further designed the details of the family support and advocacy component of the partnership. Out of these meetings came the decision to funnel the funds through *FIT*. This example underscores the idea that working out the relationship between advocacy organizations takes commitment to the process, a willingness to work things out, and a mechanism for bringing people together.

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*Working out the relationship between advocacy organizations takes commitment to the process, the willingness to work things out, and a mechanism for bringing people together.*

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Another way the family-provider partnership evolved was through the consistent involvement of Susan Tager during the early developmental stages of the *Partnership*. She was present at many of the design meetings providing input to staff about how families would want to be treated. She was also involved in interviewing some candidates for staff positions. Having a voice in who got hired undoubtedly contributed to recruitment of a family-friendly clinical staff. Through all of this, her

opinions and input were taken seriously and considered an important part of the process, but not accepted automatically. One of the criteria for good partnership appears to be the ability of both families and professionals to listen to each other's input, reflect on it critically, and respond to the merit of the content, regardless of the source.

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*Angela Vaughn, the second Family Advocate hired, noted that because she and Susan are given responsible roles within the Partnership and listened to, others both inside and outside the Partnership treat them with respect.*

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Another aspect of the relationship that has helped the family advocates to establish themselves is the respect and responsibility given to them by Raymond Crowel, Phil Leaf and other leaders of the *Partnership*. Angela Vaughn, the second Family Advocate hired, noted that because she and Susan Tager are given responsible roles within the *Partnership* and listened to, others both inside and outside the *Partnership* treat them with respect. One manifestation of this is the way they are treated by staff from

other service sectors who are less accepting of family member involvement. According to Angela, when they see *Partnership* administrators and staff treating her as an expert, then they do likewise.

## Contacting Families

Families entering the Family Resources Coordination Unit receive information about Families Involved Together and its services as a part of the intake package. This package also includes a form that gives *FIT* the right to contact the family members and offer support if the family wants this. Most clinicians encourage family members to sign this consent form. This effectively lays to rest any concerns that might be voiced about

confidentiality and sharing of information (for example, phone numbers or addresses). Susan says that because of her experience with the National Alliance for the Mentally Ill, she knew that confidentiality would be an issue and incorporated a process from the beginning. She notes that they modified a form that was being used at the Alliance for the Mentally Ill to fit the needs of the *Partnership*. This form, with slight modifications, has served them well for the past five years.

Susan Tager and Angela Vaughn work closely with staff to meet the needs of families. Although most of their work is with families being served in the Family

Resource Coordination Unit (families with the most intense needs) they also respond to requests from clinicians in the school-based programs, particularly helping families through the school's special education process. Susan attended team meetings for both Family Resource Coordination Unit and school-based programs for a long time and she and Angela continue to do this, although they must negotiate between these meetings and other commitments and priorities. Both feel that this contact with the *Partnership* staff is invaluable and needs to be maintained.

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*A particularly powerful example of how the respect and responsibility given the Family Advocates has influenced others' attitudes is the way that flexible funds have been handled by the Partnership.*

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## **Flexible Funds**

A particularly powerful example of how the respect and responsibility given the family advocates has influenced others' attitudes is the way that flexible funds have been handled by the *Partnership*. The need for a small pot of "flex funds" was recognized early on by both clinical staff and Family Advocates. Although wraparound funds were available, there was a need for a small fund that could be accessed quickly and with a minimum of restrictive criteria. The original idea for the flex funds grew out of the availability of carry-over funds within the *Families Involved Together* contract for one year. *FIT* proposed to put those funds into a flex fund and the proposal was accepted. The flex fund became so important to both staff and family advocates that it became a line item in the *FIT* budget.

The flex funds are administered by *FIT* through a committee that Angela chairs. The committee includes a representative from each component of the *Partnership* the Family Resource Coordination Unit, School-Based Program, and the Children's Mental Health Center, as well as other staff. Requests to use flex funds can come from either *Partnership* staff or from *FIT*. Although Angela is the only family member on the committee, she says that she has significant decision-making power and the committee is usually able to come to a consensus about what to fund. Typical uses for the flex funds are for summer camp,

recreational opportunities, assistance with rent and utilities and support for youth who have graduated from the *Partnership*. This method of administering the flex fund is another example of a way that site administration can show its respect and trust for the family advocates and the family advocacy organization.

## Sustainability

The fiscal relationship between the *Partnership* and *Families Involved Together* has been a cordial and supportive one from the beginning. The contract to *FIT* has been generous (\$135,000 in the first year), and Raymond Crowel and Diane Sakwa meet yearly to discuss the line items within the budget and modify those as needed. Carry-over is granted after details for its use are provided. The *Partnership* gives *FIT* a great deal of autonomy with regard to how the resources are best used. An example of this is the annual conference that *FIT* organizes and the *Partnership* funds. This conference, which is primarily intended for family members, was well enough funded in the first two years to be held in a hotel and to support family members' attendance. Susan notes that she is given complete autonomy to plan the content of the conference with other family members. After the first year, professionals were invited to attend but the content of the conference continues to be aimed at families' needs. Staff from the *Partnership* are very involved in making presentations at the conference and Susan notes that this kind of collaboration is very important to maintaining the ongoing relationship.

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*The Partnership gives FIT a great deal of autonomy with regard to how the resources are best used.*

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As in most sites, the issue of sustaining the family advocacy organization involvement in the system of care is a difficult one. On the one hand, everyone seems to agree that the family advocacy and support

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*One of the strongest messages that one receives from visiting the Partnership and talking with the Family Advocates is the clear and common vision about the importance of family member input into the system of care.*

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component is critical, yet at the same time, this kind of service is very difficult to fund through the usual categorical funding mechanisms. Even finding matching funds (in connection with the Center for Mental Health Services grant funding) as the Center for Mental Health Services grant declines over the years, has been difficult in some sites. In East Baltimore, Raymond and other site leaders are working with *Families Involved Together* to develop a long-term funding strategy. Ideas to date include foundation funding and bidding on public funds that currently go

to other advocacy programs. The ability to sustain the family advocate positions within *FIT* after the Center for Mental Health Services grant is over will be a test of the shared vision for family-provider partnerships.

## **Unique Qualities of the Partnership**

One of the strongest messages that one receives from visiting the *Partnership* and talking with the family advocates is the clear and common vision about the importance of family member input into the system of care. The commitment to this philosophy was held by the founders of the *Partnership*, was reinforced by who was hired as director and staff, and continues to be reinforced by the respect and autonomy given to the family advocacy organization.

This strongly held common philosophy is augmented by the length of time that individuals have worked together. Diane Sakwa and Susan Tager have been involved in family advocacy since 1988, and Phil Leaf began working with them in 1991. Raymond Crowel came to the *Partnership* shortly after it was funded in 1993 and Angela was recruited in 1994. The fact that the personal relationships have been in place from 4 to 10 years helps one understand how the open and direct communication has been achieved. There is a clear sense that each person speaks his or her mind and that Angela Vaughn and Susan Tager are not afraid to go directly to Raymond Crowel when they have an issue to discuss or a concern. In fact, Raymond notes that in his experience, he knows that the family involvement mission has been achieved when they “kick down the door and say, “We’ve got to talk.” Although the positive assertiveness on the part of the family advocates is important, the receptivity of the professional to this is also critical.

The fact that the family members and the *Partnership* have worked together for five years without a major crisis may be unique to this site. In many sites, there has been a crisis in which either the family organization has changed or the mechanism for achieving family member input has been modified substantially. These crises and subsequent changes, although probably part of a normal development process in family-provider partnerships, are often accompanied by strained relationships, a break in trust and much conflict and personal hurt feelings on all sides. In the relationship between the *Partnership* and *Families Involved Together*, although both can point to some conflictual moments, there has been no major breakdown of communications. This is due to the commitment to collaboration, mutual respect and establishing and fostering win-win situations as well as the longevity of the working relationships and willingness to talk about concerns and differences.

## **Strengths and Limitations**

One of the major strengths of having the family advocacy and support work contracted to a separate, independent family organization is the autonomy afforded the Family Advocates. They can speak more freely about the limitations of the system of care or complain about the services that a family is getting without fear of losing their job. In fact, they are perceived as doing their job well when they give critical



input to the system of care and individuals involved. Further, the family members who are receiving the support may see the Family Advocates as unattached to the service system and therefore, less likely to stigmatize, blame or otherwise discount the needs of the family.

One limitation of housing the family advocates in a different location than the *Partnership* is the challenges this presents to ongoing communication and problem solving. Because the family advocates are on the *FIT*, they must attend *FIT* staff meetings and have functional duties regarding the maintenance of *FIT*. These tasks take away from their time to function as family advocates and may conflict with scheduled staff meetings at the *Partnership*. Because their offices are in a different place, they may not be around for informal discussions or casual contact in the hall between meetings. Consequently, Susan Tager and Angela Vaughn have to spend a certain amount of time just “hanging around” the *Partnership* and attending staff meetings in order for their presence and services to be fresh in the providers minds. The balance between autonomy and availability is one that has to be finely calibrated and revisited often.

## **Suggestions for Implementation at Other Sites**

According to both Susan Tager and Diane Sakwa, “there is nothing that we do that couldn’t be done elsewhere.” Diane noted that although they have an unusually high level of support from the leadership at the *East Baltimore Mental Health Partnership*, that most of what they are doing could be done in other communities. Family Advocates and professionals should consider use of training, role modeling, and a commitment to collaboration as a means to promote strength and effective resources with families. Raymond Crowel commented that actively supporting family member partnerships takes the will and the political position to be able to move money around. He concurs that what has happened in East Baltimore can be recreated elsewhere.

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*According to both Susan Tager and Diane Sakwa, “there is nothing that we do that couldn’t be done elsewhere.”*

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## Chapter III

# Resources for Family-Provider Collaboration

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### HAWAII OHANA PROJECT AND HAWAII FAMILIES AS ALLIES

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#### *Promising Practice*

*Broad participation of family member, as community council representatives,  
and as designers and implementers of surveys.*

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In September 1994, the Hawaii State Department of Health was awarded a Center for Mental Health Services grant for the *Hawaii Ohana Project*. The *Ohana Project* directs funding and resources toward expansion of Waianae Coast Community Mental Health Center (WCCMHC) services, as well as toward Susannah Wesley Mental Health Center. In 1994, the *Ohana Project* asked *Hawaii Families as Allies* (a family organization already in operation) to partner with them in efforts to involve families in the development of effective services to children with serious emotional disorders and their families.

Beginning in the 1960s, the Hawaii state legislature established Waianae Coast Community Mental Health Center as a community-based privatized mental health system of care. In response to a class action lawsuit filed against the Department of Health and Education in 1991, the state was mandated to implement a statewide system of care for children with serious emotional disorders based on the Child and Adolescent Service System Program principles.

The central objective in the *Hawaii Families as Allies*' mission statement is to provide information, education, support, technical assistance, and referral to families of children with serious emotional disorders. *Hawaii Families as Allies* works statewide; two mental health sites fall under the Center for Mental Health Services grant funds: The Susannah Wesley Mental Health Center and the Waianae Coast Community Mental Health Center provide mental health services.

Broad family involvement in Hawaii children's mental health systems of care is particularly important because of the culturally diverse nature of children and families that the mental health sites serve. The implementation of family participation supports services that respond to diverse community strengths and

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*One tool particularly important to family participation and family-provider collaboration are surveys that were designed and are implemented by families.*

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needs. Family members hold important positions as children's community council representatives. As representatives, family members contribute to at least one-third of the program's assessment, evaluation, assistance, and development review process.

One tool particularly important to family participation and family-provider collaboration are surveys which were designed and are implemented by families. The surveys are used to determine the quality and effectiveness of services. These that have been instrumental in identifying families' needs and priorities and in assisting in the development of new services. In this way, families are a guiding tool for mental health service systems. Because the surveys impact services, are delivered by families, and reach many families, they are directly supportive of family-provider collaboration and are responsive to diverse community values.

## **KANFOCUS AND PARENT T.E.A.M.S., SOUTHEAST KANSAS**

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### ***Promising Practice***

*Use of focus groups to assess family priorities and to support development of family organization; attention to sustainability at the levels of mission, credibility in community, and finances.*

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The Center for Mental Health Services began funding the *KanFocus* project in 1994. Administratively managed by the Labette Center for Mental Health in Parsons, Kansas, *KanFocus* works with five community mental health centers to provide services for children with serious emotional disorders in a 13-county region. *KanFocus* serves a decidedly rural population. Services are also offered to children who are at risk of out-of-home or out-of-community placement.

Family participation and family-provider collaboration within *KanFocus* has occurred in a variety of ways. Keys for Networking, a statewide family organization (connected with the Federation of Families for Children's Mental Health) coordinated the work of Family Advocates, and supported families organizing in each community. In the interest of drawing on local and community resources, *KanFocus* decided to explore potential leadership among families living in southeastern Kansas. Over the last few months, family participation in *KanFocus* has been coordinated through a group of Family Advocates hired and financially supported through KanFocus. This group of family advocates has been organizing with family members

throughout the 13 counties since January 1998. Their work has resulted in an 18-member board of family members and in an independent family organization, *Parent Training, Education, Advocacy, Mediation and Support* (T.E.A.M.S.), that is meeting regularly and working toward non-profit status.

This profile will feature the work of that 18-member board since January 1998. Following conversations with numerous participants in systems of care across the United States, we define sustainability as minimally involving attention to:

- the mission of the organization
- the organization's credibility in the community
- finances

The work of family members in Southeastern Kansas is particularly relevant to the challenge of sustainability because of their commitment to addressing all three components. This profile will detail the steps family members in Southeastern Kansas are taking to develop an independent family organization.

## **Background to Family Participation in Children's Mental Health Services in Southeastern Kansas**

As in many communities, family involvement in children's mental health systems of care in southeastern Kansas has not always proceeded easily. Issues particular to southeastern Kansas have included and often continue to include:

- a reluctance among family members to have their children labeled by mental health agencies as seriously emotionally disturbed; and
- rumors that family members in southeastern Kansas were not interested in being involved in children's mental health systems of care.

Additionally, a critical value for family members in Southeastern Kansas is that organizations come from within their communities. (*Parent T.E.A.M.S.* defines "parents" and "family members" as "those who have significant care taking involvement in the lives of . . . special needs children.")

At a time when local family participation in children's mental health services was still emerging, *KanFocus* saw an opportunity to reevaluate the involvement of families in children's mental health systems of care in southeastern Kansas. Staff at *KanFocus* decided it would be appropriate and important to use focus groups to ask several foundational questions of family members, addressing issues including who might be involved in a family organization, and how a local family organization would be organized and structured.

*Parent T.E.A.M.S.* has developed largely as a result of focus groups conducted by Rose Murphy and several other family members in southeastern Kansas. These focus groups have required a significant commitment of time and dedication to the process, and have often been simultaneously encouraging and exhausting. In addition to the leadership of several family members in Southeastern Kansas of the focus groups, support and funding from KanFocus has also been critical to the foundational work of developing an independent family organization. In Southeastern Kansas, it has been both the backing of a community mental health system of care and the commitment and dedication of several family members that enabled the process of focus groups and the pending existence of an independent family organization. Particularly important, and we believe relevant to other communities interested in creating an independent family organization, is the consistent attention *Parent T.E.A.M.S.* has given to mission, credibility in community, and finances.

In January 1998, Rose Murphy began the process of addressing family involvement in children's mental health systems of care in southeastern Kansas through a full-time practicum position. Ms. Murphy came into the practicum as a student completing a degree; she also had cared for children who received mental health services. Ms. Murphy had the responsibility of facilitating the design and coordinating the implementation of the focus groups. In June 1998, she became a full-time paid staff person at *KanFocus* (in a temporary position that lasted through September). The remainder of this profile addresses the history and structure of the focus groups, as well as *Parent T.E.A.M.S.* attention to mission, credibility in the community, and financial situation.

## **Structure of Focus Groups**

The design and structure of the focus groups were critical components to the process of gathering family members' input. The initial ways in which families establish a connection to the system of care are critical to the development and sustainability of any family organization; parents in southeastern Kansas thoroughly thought through the organization of the focus groups, clearly articulating goals, recruitment process, implementation, guidelines for participation in the focus groups, and questions and issues to be addressed at the focus groups. This careful and intentional concern for the process of gathering family members' input significantly contributed to the development of a mission statement as well as the credibility of *Parent T.E.A.M.S.* in the community. Additionally, families in southeastern Kansas drew on strong family support resources. Liz Sweet (currently with the Child, Adolescent, and Family Branch of the Center for Mental Health Services) facilitated the focus groups and Beth Dague (a consultant for Community-Based Systems) assisted in the initial planning process.

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*Staff at KanFocus decided it would be appropriate and important to use focus groups to ask several foundational questions of family members.*

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Family members who designed the focus groups established two primary purposes:

- to gather input on current issues, and
- to determine if parents wish to take this opportunity to begin to build an organization that will allow them to continue to participate in a collaborative effort on behalf of their children.

Further, family members acknowledged that current availability of funding for the focus groups made it particularly timely to begin the process of gathering parents' input. Family members planning the focus groups addressed several additional issues, including:

- Gathering parent support should be controlled by parents rather than professional services or advocacy agencies.
- The targeted parent group would include anyone parenting a child with a severe emotional disturbance (including parents who served in a professional role in mental health services).
- A key value was to involve as many parents as possible.

These choices and values provided a framework for the work of *Parent T.E.A.M.S.*, and are directly linked to the areas of mission, credibility in community, and finances.

## **Mission**

The mission statement was developed by parents connected to children's mental health systems of care in southeastern Kansas. Of the 18 parents on the Board of Directors, approximately 12 were actively involved in writing the mission statement. In July 1998, this group of parents officially opted the name *Parent T.E.A.M.S.*, and wrote the mission and goals statements. At this time, parents also elected a board of directors, hired a family coordinator, and created committees.

## **Credibility in Community**

As stated previously, the structure of the focus groups has been centrally important to the role *Parent T.E.A.M.S.* has in southeastern Kansas. The board specifically targeted two groups of family members for the focus groups:

## **PARENT T.E.A.M.S. MISSION STATEMENT**

**Parent T.E.A.M.S.** mission is to: create a structured organization built on the strengths, wisdom, and talents of our membership that is dedicated to provide training, education, advocacy, mediation, and support to all members of the community who are invested in the lives of our children.

**Our goal is to:** increase family participation in collaborative efforts to insure a system of care that values children and their families and responds to their individual needs to insure that all children have full and equal access to opportunities to succeed, as they define their own success.

The **T.E.A.M.S.** initials stand for the areas of training, education, advocacy, mediation, and support.

- parents with children currently receiving services; and
- parents whose children qualify for services but are not currently receiving services.

The board developed questions for the focus groups that addressed:

- strengths parents could offer for parent to parent support;
- needs parents have for support; and
- parent participation in planning and evaluation.

In addition to hiring an outside facilitator from a national family organization, *Parent T.E.A.M.S.* developed a set of “rules for participation.”

*Parent T.E.A.M.S.* utilized a three-pronged recruitment process for the focus groups. First, involved parents from a majority of the 13 counties formed a regional planning committee, and organized and invited parents to a “pre-meeting.” Next, at the pre-meeting, parents set an agenda for the focus group meetings, and discussed facilitation, child care, and post-meeting follow-up. Pre-meeting participants each committed to invite at least five additional participants. Finally, directors of mental health services encouraged their case managers to invite participants to the focus groups in their area. *Parent T.E.A.M.S.* held 23 meetings, primarily in the evenings and on weekends. In addition to holding groups with parents, *Parent T.E.A.M.S.* held three focus groups for professionals and three meetings for adolescents.



Over 150 people participated in the focus groups. Family members, adolescents, and professionals were frank and eager to communicate their experiences and ideas. Meetings drew a wide variety of people from southeastern Kansas, including representation across race, socio-economic class, and level of classroom education. Organizers' clarity regarding rules for participation and focus group objectives demonstrated respect for participants' time and energy, and ensured that focus groups would meet the two primary objectives of the focus groups that the board had identified.

## **Finances**

Links between mission, credibility in the community, and financial sustainability are particularly clear in southeastern Kansas. The mission statement developed by *Parent T.E.A.M.S.* provided a framework and direction for the focus groups. *Parent T.E.A.M.S.* intentionally sought out a wide variety of families; this supported connection with many different representatives of the counties involved. Financial sustainability in southeastern Kansas will be directly linked to outcomes of the 23 focus groups.

Financial support for *Parent T.E.A.M.S.* has come in many forms. Meeting and child care rooms, child care itself, food for the meetings, as well as support from mental health centers, coalitions, Head Start centers, churches from many denominations, libraries, education centers, family centers, parent support persons, children's advocates, case managers, therapists, attendant case workers, university students, special education teachers, and professional child care centers were all forthcoming throughout the focus groups. The above people and organizations have been generous with donation of in-kind services as well.

*Parent T.E.A.M.S.* also is working out issues of sustainability at the level of long-term funding. Initial conversations with other agencies (for example, services for adults with severe mental illness and employment agencies) have led to the possibility of collaborative funding. Mental health centers throughout the 13 counties have committed to provide funding. *KanFocus* will continue to pay a parent to coordinate family members. As Rose Murphy states, a critical component of sustainability for parents in southeastern Kansas is commitment, on the part of parents and providers, to family participation in children's mental health services.

## Conclusion

*Parent T.E.A.M.S.*, with the support of *KanFocus*, has gone through a time-intensive and in-depth process to involve family members in new and significant ways in children's mental health systems of care in southeastern Kansas. They have given considerable attention and energy to the initial questions in forming a sustainable and independent family organization. It is this commitment to the process of articulation of mission and goals, and to significant and broad-based family member involvement, that we see as fundamental to any independent family organization achieving sustainability at all levels.

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*Over 150 people participated in the focus groups. Family members, adolescents, and professionals were frank and eager to communicate their experiences and ideas.*

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The Board of Directors of *Parent T.E.A.M.S.* meets every 1 to 2 weeks; 503(c) status is a goal toward which they are working. In addition to sharing the results of their focus groups with family members in southeastern Kansas, they have developed a list of "lessons learned" from the focus groups and documented the process and guidelines they followed.

*Parent T.E.A.M.S.* is a young organization. They are a group of family members committed to a process that is time consuming and often difficult. We hope our discussion of this process might provide ideas and offer resources and support, particularly to participants in systems of care committed to broad-based family participation and the existence of independent family organizations.

## NORTH DAKOTA PARTNERSHIP PROGRAM AND NORTH DAKOTA FEDERATION OF FAMILIES

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### *Promising Practice*

*Family members are becoming equal and regular partners  
in developing the system of care.*

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## History and Background

The *North Dakota Partnership Project* is a Center for Mental Health Services-funded children's mental health system of care project that began in late 1994. Funds are dispersed to three regional Human Service Centers in the state: Region II with offices in Minot; Region VII, centered in Bismarck and Region V,

served by Fargo. This service site has just finished its fourth year of operation. *North Dakota Partnership Project* has a strong partnership with the North Dakota Federation of Families, a family advocacy organization that offers support, disseminates information, and advocates for families and children. Family members are equal and consistent partners in the development of the system of care.

The *North Dakota Federation of Families* has successfully worked out a balance between a central organization and the need for local autonomy. The state office for the Federation is situated in Bismarck, although the three Parent Coordinators are located in their respective regions. The three regions have had the flexibility to develop a structure and strategies that meet their local family advocacy needs. A large portion of the Federation budget comes from the Center for Mental Health Services grant, although the Federation also has a separate contract with the state to provide respite care training. Currently the North Dakota Federation is functioning with an interim Director because the past director left to work for the federal government.

The *Partnership* contracts with the North Dakota Federation to provide training and support services to families in North Dakota. Through the Federation, three Parent Coordinators are employed, with one assigned to each Region. The Federation, through its volunteers and through the Parent Coordinators, works with all families who need support because of their care-giving role for a child with a serious emotional disturbance. Families may join support groups or get help from the Parent Coordinators even if they are not receiving services from a *Partnership* site.

## **Partnership Council**

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*The chair of the Council must be a family member whose child is currently receiving services. The aim of this structure is to assure full partnership of families at all levels of planning, decision making, and policy setting within the system of care.*

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Each of the three Regional Human Services Centers has an advisory council that advises the Human Service Centers on site activities. Regional Partnerships Advisory Councils are made up of four core representatives: Mental Health, Education, Juvenile Justice and Child Welfare, along with representatives from regional agencies and family members. In Region VII, this body is termed the North Dakota Partnership Council, and has approximately 21 members with 51 percent of the membership filled by family members of children with serious emotional disorders. In this Region, the chair of the Council must be a family member whose child is currently receiving services. The aim of this structure is to assure full partnership of families at all levels of planning, decision making, and policy setting within the system of care.

The Parent Coordinator for Region VII serves as the chairperson for the Council. In addition to the family members who serve on the Council proper, there are five standing committees, all of which have family member representation. Family members can be involved with the Council or one of its committees even if their special needs child is not currently receiving services from the *Partnership*. In a state that is sparsely populated, it is a particular challenge to identify family members who wish to be involved in the Council and help them remain active. Family members work hard to get to meetings whenever they can, but this is difficult if their child is in crisis. A parent stipend is made available to families to increase their involvement in council meetings. Families mentor each other at meetings, trying to make sure that no one person is the repository of critical information.

## **Police Youth Bureau Protocol**

One example of the collaborative process that has emerged from the Partnership Council was initiated by the Director of the Police Youth Bureau. Influenced by information obtained through Council meetings, the Police Youth Bureau decided to change the protocol used to respond to calls from schools asking for advice on how to handle behavioral situations. Working with the Parent Coordinator and another family member, the protocol was changed so that the language is more consistent with special education philosophy. The protocol now contains questions such as “Have you done a behavioral assessment?” and “Is this behavior a manifestation of the child’s disability?” This change in protocol has changed the perspective with which Youth Bureau staff view young people with behavioral difficulties. Although not generated in a Council meeting, this system change emanated from relationships developed through the Council.

## **Health Tracks**

Another example comes from the local County Social Services, whose director is a member of the Partnership Council. The Department of Human Services’ Health Tracks Screening System is a process for assessing and referring children who are eligible for Medicaid (formerly called Early Periodic Screening, Diagnosis and Treatment, EPSDT.) The County Social Services Director thought it might be useful to have a child with an emotional disability screened by Health Tracks as a way of testing the systems’ effectiveness in identifying this disability and testing the family friendliness of the screening system.

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*One of the keys to the solid family and provider relationships in North Dakota seems to be the longevity of the personal relationships involved.*

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The Parent Coordinator volunteered her child for this test, went through the screening process and then provided feedback to the County Social Services Director, County

Health Tracks Coordinator, and State Health Tracks Coordinator about the process and areas that could be improved. As a result, the Department is now looking at the consistent use of a mental health screening tool. This review has implications for the Health Tracks System statewide and has moved beyond Region VII to a state level. Unfortunately, up until now not all children were screened for mental health problems unless the parents asked for it or unless behavior difficulties were obvious. Again the idea for this system change was sparked by the director's membership on the Council and was implemented because of his relationship with family members who also served on the Council.

## **Long Term Relationships**

One of the keys to the solid family and provider relationships in North Dakota seems to be the longevity of the personal relationships involved. The past Director of the Federation of Families, the Administrator for Children's Mental Health and the Director of Mental Health and Substance Abuse Services have longstanding relationships that predate the founding of the *North Dakota Federation of Families* and the receipt of the Center for Mental Health Services grant. These relationships have been built on a foundation of trust. In fact, these individuals indicate that prior to the application for the Center for Mental Health Services grant, they "agreed to disagree." Each individual knew that there would be disagreement over the implementation of the grant or other related issues. However, the important point was to have each representative coming back to the table to share his or her perspectives on the various issues that arise when developing systems of care for youth with severe emotional disorders. This trust allowed each to dedicate energy to his or her own job without expending energy monitoring the other. Each person indicated that "partnering doesn't necessarily mean agreeing."

## **DREAM CATCHERS FAMILY ADVOCATES SOUTHERN OHIO CONSORTIUM FOR CHILDREN**

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### **Promising Practice**

Working at sustainability through wise use of resources, offering services that are billable, and exchange of information with other family advocacy groups.

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## **Background**

*Southern Ohio Consortium for Children* shares a Center for Mental Health Services grant with Stark County, Ohio, although the consortium functions as a separate entity. The *Southern Consortium*

serves three rural counties of Adam, Lawrence and Scioto in southeast Ohio. Based in Athens, it provides services to Appalachian children and adolescents with serious emotional disturbances and their families in their homes and schools.

## **Sharing Knowledge: The Key to Sustainability of Family Organizations**

Dream Catchers Family Advocates Inc. is a relatively new family advocacy organization developed in tandem with the advent of the Center for Mental Health Services system of care. As with all new organizations, sustainability is a major concern. Stephanie Wright, family coordinator for Dream Catchers Family Advocates, feels that there are three important considerations that will help achieve a stable future for her organization.

The first important consideration is to avoid spreading the family organization's money, time, energy and resources too thinly. Under the original grant plan, the service site and Dream Catchers were trying to serve 10 counties in Southern Ohio. As with other aspects of the system of care, the family advocates found that there were many diverse issues and conflicting views of what their role should look like across the counties. The decision to reduce the focus of the system of care to 3 of the original 10 counties supported Dream Catchers' ability to develop and sustain the integrity of the family advocate.

The second factor in sustaining the family organization is ensuring that the role Dream Catchers Family Advocates play in the interagency system of care is identifiable as unique, necessary, and offers services that are billable. Stephanie Wright said that she came to recognize that Dream Catchers is a business. Family members working in that organization need to view their work as being part of a business so that Dream Catchers Family Advocates can hold equal ground and influence with other agencies. For example, if Dream Catchers is not considered an equal member of the interagency group, Family Advocates could be excluded from serving families involved in multiple agencies because of restrictions around confidentiality.

Dream Catchers secured permission to utilize a consent form from the Families and Children First Council requesting access to confidential information. The consent form asked families to check off each type of agency information that the family advocate could have access to, such as mental health, probation, and school records. This gave the family organization the ability to be equal team players at family-provider meetings and ensure that families were getting all of their needs met.

In order to sustain themselves after the grant money runs out, Dream Catchers needed to develop contracts with other agencies so that it could meet Ohio's "community support rule," which allows the family

advocate's work to be billable through Medicaid and through other funding agencies. Stephanie reported that in Ohio it was necessary to document their work and develop guidelines that showed that the family organization serves a different need from agencies. The "community support rule" pertains to agencies who provide advocates that represent individuals who are receiving services from several community agencies. Dream Catchers developed guidelines that clearly described the job responsibilities of the family advocates and is now developing a policy and procedure manual that describes the scope of the business. After some in-depth background research, Stephanie found that agencies could bill Medicaid for "family advocate" services if the job title was changed to "community support representative." She admits that some of the Family Advocates dislike the rigidity of this new business perspective and have left the position.

The third consideration that will support the sustainability of the family advocacy organization is the exchange of information with other family advocacy groups. By talking with more established family

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organizations, Stephanie learned about legal resources, the importance of policies and procedures guidelines, and Medicaid rules for reimbursement of services. Through the advice of other family coordinators, she is now learning to develop small contracts with other agencies such as mental health, probation, and education. Under these contracts, Dream Catchers will commit a set number of hours each week that can then be billed

through Medicaid. Stephanie strongly encourages other family coordinators to reach out to established family advocacy organizations and utilize as much as possible, their experience and expertise on how to survive.

Dream Catchers is an example of a family advocacy organization that has chosen to become like a small non-profit social service agency in order to survive financially. Although this model has its limitations in the form of reduced autonomy, the benefit is the stability and security that allows for the family advocate role to become well established, known and skillful within the community.



## **VERMONT ACCESS PROJECT**

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### **Promising Practice**

Development of training curriculum (including manuals and videos) that empowers parents to become leaders and advocates within systems of care.

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The *ACCESS Project* is one of the few Center for Mental Health Services grants that was designed to serve the whole state. The grant funds were received by the Vermont Department of Developmental Disabilities and Mental Health Services and disbursed to the 12 regions with the charge to develop services for children that met the needs of the region. This purposeful decentralization of services allowing local communities to design and run systems that are useful to them represents a change in philosophy about how to structure and administer services. Interagency collaboration and family member participation have a strong history in Vermont, where both aspects of the system of care have been mandated through legislation for a number of years. Each of the 12 regions has employed a slightly different strategy for organizing services and ensuring family member participation at all levels of the service system.

Family advocacy and organizing also has a long history in Vermont. The Vermont Federation of Families, with Judy Sturtevant as Director, was founded in 1989 under funds allocated from the Child and Adolescent Service System Program grant in Vermont. This statewide organization has been responsible for organizing support groups, telephone information and referral, parent-to-parent support, and advocacy throughout the state. In addition, the Vermont Federation of Families has participated in system change at the legislative level by working collaboratively with other advocacy organizations. Although each of the 12 regions has its own unique approach to supporting and structuring family member support and participation, the Federation continues to coordinate activities that have a statewide scope. Consistent with the change in philosophy toward decentralized services, the Vermont Federation of Families is also working to decentralize family support and advocacy efforts and to help family members in local communities build support systems that meet their communities' needs.

### **Leadership Training**

The need to develop and deliver parent leadership training became apparent once the Vermont Federation of Families adopted the strategy of decentralizing family support and advocacy activities. As a part of their statewide mission, the Vermont Federation of Families agreed to develop and disseminate a curriculum that would help local family members become leaders in the regional system of care and advocates for children's mental health services. This task was written into the contract between the

Federation and the Vermont Department of Developmental Disabilities and Mental Health Services prior to the funding of the service sites. Because the Federation had

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*As a part of their statewide mission, the Vermont Federation of Families agreed to develop and disseminate a curriculum that would help local family members become leaders in the regional system of care and advocates for children's mental health services.*

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been responsible for training and coordinating the parent representatives on the interagency teams under the Child and Adolescent Service System Program, they had the experience and knowledge to tackle this set of activities.

Initially Judy Sturtevant developed a curriculum that required 15 hours to complete; she piloted it in two regions.

Based on the feedback from those parents, the content was modified. Then Judy heard about a Leadership Training program in Connecticut and arranged for two of the Federation staff to attend. This experience provided the missing piece for the developing curriculum. The original 15-hour curriculum was focused primarily on providing information about system of care, mental health services, system procedures and processes. The recommendations that the staff brought back incorporated the concept of empowerment: supporting a mindset among family members to make changes and helping them understand that they could make change happen. This modification resulted in the development of a 30-hour, 10-week curriculum under the title "Individuals in Community Advocacy and Networking" (ICAN).

The content of the 10 weekly sessions was developed and designed by family members using feedback from many different parents. In addition to the curriculum, the Federation has also produced a Trainers' Manual, a manual for the trainees, and four videotapes to be used with the training. The four videotapes cover the following topics: (1) overview of the curriculum, (2) family/professional partnerships, (3) advocacy, and (4) collaborative team building. Family members who participate in this training are expected to take on roles as parent leaders within their home region, including training new groups of family members.

Three family members work together to co-conduct the training, which meets once a week for three hours. Judy Sturtevant and Edie Hewitt from the Vermont Federation of Families staff have been involved in delivery of all training to date. In addition, they invite a family member from another region who has been through the training to help co-train. This gives that person some experience and skill in delivering the content so they can go back to their home region ready to train a new group of parents. The training is interactive, with many planned experiences that

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*The training is interactive, with many planned experiences that help family members get to know each other, and build confidence in themselves and their ability to be a part of system planning and change.*

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help family members get to know each other, and build confidence in themselves and their ability to be a part of system planning and change. Topics covered include discussion of how change happens and how parents can function as change agents. Issues of cultural competence and skills of conflict resolution are also emphasized. Content specific to legislation and the service system within Vermont is included as is an opportunity for the family participant to begin work on forming a regional family group.

The funding for the development of the curriculum and materials was shared by the Vermont Department of Developmental Disabilities and Mental Health Services and the *ACCESS* grant. The regions are asked to pay for the cost of the training, which averages \$1,000 in each community but can go higher if a larger group of family members participate. Family participants are reimbursed for their child care and travel, and receive a stipend of \$50. In addition, refreshments are served at each session. The local families decide when they want the training to occur and are responsible for designing a formal graduation. According to Judy, some of the graduation ceremonies have been elaborate, with commencement speakers such as the Vermont Lieutenant Governor and Captain Kangaroo. Each graduate also receives a certificate of accomplishment and a T-shirt.

The curriculum has now been delivered in 10 of the 12 regions. The other regions are scheduled for training in the coming year. Some regions have elected to repeat the training as new parents begin working with the service system. One region has just scheduled its third group of family members for training. The curriculum content and training procedures continue to be evaluated and fine tuned as family members make suggestions. This approach to working with family members with the skills and interest to assume local leadership positions responds to the following need identified by Judy: "Parents want the content, they want information and they want to know how other parents did it." Family members are often looking for a way to give back to the community and to make sure that other families don't suffer difficulties with the service system. Experiences such as the I CAN training give family members knowledge, skills, and the feeling of empowerment that allows them to become an integral part of the system of care.

## **KMIHQITAHASULTIPON PROGRAM, INDIAN TOWNSHIP, MAINE**

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### **Promising Practice**

Four week intensive training program (and ongoing weekly staff meetings) that support careful attention to vision and goals and to diverse community values and norms.

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The *Kmihqitahasultipon Program* serves children and families of the Passamaquoddy Tribe of Indian Township, Maine. Initially funded by Wings of Maine, the *Kmihqitahasultipon Program* began receiving Center for Mental Health Services grant funds (independently of Wings of Maine) in 1997. The *Kmihqitahasultipon Program*, the name of which means "we remember" in Passamaquoddy, works with a

major goal of “restor[ing] Passamaquoddy culture and traditions to the daily life of Indian Township families and children for the purpose of improving overall community well-being.” Based on Passamaquoddy tribal values and beliefs, the *Kmihqitahasultipon Program* is “bringing back what was once here.” The project offers home-based care consistent with Passamaquoddy approaches to healing and community well-being in a population of 900 people, 60 percent of whom are under the age of 24.

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***B**ased on Passamaquoddy tribal values and beliefs, the *Kmihqitahasultipon Program* is “bringing back what was once here.”*

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This profile features a training program that eight of the current staff attended at the beginning of the Passamaquoddy Tribe’s work with Wings of Maine. The training took place over the course of four weeks, and was a requirement for all project staff. In addition to covering issues central to children’s mental health systems of care, the staff attending the training developed and solidified a way of working together that supports an ongoing commitment to the vision and goals of the *Kmihqitahasultipon Program*. As the staff stated, the vision of the *Kmihqitahasultipon Program* “reflects the heart of the community, the beat of the drum, and a belief in the spirit of the community.”

Because Passamaquoddy culture and values support children’s mental health care that is fundamentally family-centered and that understands families as central to a child’s healing process, the *Kmihqitahasultipon Program* provides insight into family-provider collaboration. In particular, the training program and ongoing attention to vision and goals has resulted in a remarkably consistent staff situation: since the training, two staff have been added and all of the original eight continue to work at the *Kmihqitahasultipon Program*. The design and implementation of the *Kmihqitahasultipon Program* training offers a promising practice that is particularly supportive of clarity regarding vision and goals, and an understanding of and respect for diverse community values and cultural realities.

## **Background to the Kmihqitahasultipon Program**

The *Kmihqitahasultipon Program*, located in Indian Township in northern Maine, began its work in cooperation with the *Wings of Maine Project*. In 1996, the Passamaquoddy Project was initiated between *Wings of Maine* and the Passamaquoddy Tribe, which resides in the most rural section of the *Wings of Maine* catchment area. At that time, the Passamaquoddy Project hired staff from within the Passamaquoddy community to offer wraparound services including therapy, respite, in-home behavioral and one-on-one care specialist services, parental education, and substance abuse treatment. The training program this profile addresses occurred shortly after the Passamaquoddy Tribe began working with *Wings of Maine*.

The *Kmihqitahasultipon Program* was awarded a five-year grant that began in 1997. Staff work within Passamaquoddy cultural realities to provide individualized, team-delivered, family-based, in-home

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*An important component of the Kmihqitahasultipon Program is education and support directed at reculturation, or the reestablishment of Passamaquoddy values and traditions within the Indian Township.*

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services to families and children living in the Passamaquoddy Indian Township. Programming and services include parent education, child behavior, one-on-one services, respite, mental health counseling, and substance abuse counseling. An important component of the *Kmihqitahasultipon Program* is education and support directed at reculturation, or the reestablishment of Passamaquoddy values and traditions within the Indian

Township. The Passamaquoddy tribe maintains tribal sovereignty, which is recognized by the state and federal governments. Socio-economic stressors impact heavily on the Passamaquoddy population: unemployment is at 50 percent, all families have one or more members impacted by substance abuse; and approximately 75 percent of the Passamaquoddy population are survivors of childhood sexual abuse.

## **The Kmihqitahasultipon Training Program**

Passamaquoddy tribal values and beliefs support a family-centered approach to children's mental health services. In a Native American value system and belief framework, the concept of family-provider collaboration is ill-fitting. Simple application of the idea of family-provider collaboration to Native American contexts does not take into account profound differences between Native and non-Native approaches to children's mental health. (See the section on the *K'e Project* in this monograph for further attention to the significance of Native American understandings of mental health). The design and depth of the *Kmihqitahasultipon Program* training affords the attention to vision and goals, and community background and values that a family-centered system of care requires.

Family-provider collaboration does not occur without significant and ongoing discussion around family strengths, needs, and cultural realities. *Kmihqitahasultipon Program* staff committed four full work weeks (eight-hour days, five-day weeks) to developing and articulating the framework and components of their system of care. As a result of this four weeks, there was a subsequent commitment to full-day weekly staff meetings where the in-depth planning and discussion that occurred at the training continues. Additionally, the entire staff participates in ongoing staff development on a monthly or twice-monthly basis. Thus attention to vision and goals, and to providing services that fit the community's values and culture, is structured into the *Kmihqitahasultipon Program*.

The four-week training covered topics including an overview of *Wings of Maine*, the dynamics of change within individuals and the Passamaquoddy community, loss issues, crisis intervention skills, home visiting, counseling skills, parent education, child development, childhood mental health diagnoses and their implications, skill building for parents, child abuse and neglect, and case management, all within the community's cultural context. Training of program participants also devoted significant time addressing the ways in which Passamaquoddy history impacts delivery of services to Passamaquoddy children and families. Particularly relevant factors in the Passamaquoddy community include:

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***Kmihqitahasultipon Program***  
*staff committed four full work weeks to developing and articulating the framework and components of their system of care.*

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- cultural assimilation
- social services that were in opposition to Passamaquoddy values and culture
- forced removal of youth and adults from the reservation

The next two sections will examine the ways in which the *Kmihqitahasultipon Program* training program addressed vision and goals and the development of services that respond to diverse community values and cultural realities.

## **Vision and Goals**

As stated previously, the central objective of the *Kmihqitahasultipon Program* is to offer mental health and related services in a culturally and traditionally based manner to families and children in order to improve community well-being. The training program acted on this goal throughout the four weeks. Staff began by discussing individual expectations and hopes for the project. Conversations in the first week focused on individual staff members' experience and background, in professional areas as well as in connection with their identity as members of the Passamaquoddy community, and with their own personal histories.

Through these conversations, it became clear that two central issues for the staff were:

- *Parents' energies and resources.* Because of socio-economic stressors, parents are often primarily concerned with survival, and need a variety of strength-based interventions that are tailored to individual needs.



- *Recreating hope.* In the Passamaquoddy context, it is essential for staff and families to provide hope and to be strength-based in order to support change within the Passamaquoddy community as well as within the individual family.

Thorough and intentional discussion of staff members' priorities, expectations, and dreams for the program continues to support a clear and intricate vision of the *Kmihqitahasultipon Program's* delivery of services. The mission statement was developed shortly after the training, and thus was able to reflect the concerns and directions staff articulated at the training.

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### **The Kmihqitahasultipon Program's Mission Statement:**

**We believe that individuals should be treated with respect, honoring the paths we all have taken through past trials and tribulations.**

**We believe people grow, change and react in ways to accommodate individual differences and past pain.**

**We support and encourage the best in each family and individual, acknowledging that people do the best they can.**

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### **Respect for Diverse Community Values and Cultural Realities**

The time framework of the training program provided staff with the opportunity to carefully address how services would be particularly relevant to Passamaquoddy families and children. Previous service providers in the Passamaquoddy community were non-tribal members with no awareness or knowledge of Passamaquoddy culture, language, or values. Of the current 10 staff at the *Kmihqitahasultipon Program*, 9 are Passamaquoddy and have direct links to the reservation. Nine of the staff are familiar with the Passamaquoddy language, and five are fluent in Passamaquoddy. The training encouraged staff to draw on their own experiences in identifying strength-based approaches to delivery of services. In this sense, services are a way of respecting families' internal strengths and strategies for well-being, rather than imposing a treatment plan external to the family.

Staff also recognized the strengths in their awareness of Passamaquoddy language, values, and knowledge. Articulating these strengths is a primary means of respecting families' beliefs and values, as well as locating a kind of starting point for services. It is clear to staff that natural support systems, or support systems that already exist as an integrated aspect of Passamaquoddy family life, are frequently more valuable than support systems offered by an outside provider or the delivery of services external to



Passamaquoddy culture and values. Through the four-week training program, staff had the opportunity to talk through and articulate what a community-based and family-centered system of care would look like, as well as to draw strong connections between their own experiences as Passamaquoddy community members and the realities of the families and children to whom they offer services.

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*Through the four-week training program, staff had the opportunity to talk through and articulate what a community-based and family-centered system of care would look like.*

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## **The Kmihqitahasultipon Program Training Program and Family-Provider Collaboration**

The *Kmihqitahasultipon Program* training program offers insight into family-provider collaboration at systems of care through offering one training model that provided the time and space required to develop a community-based, family-centered system of care. While ongoing training is critical to family-centered systems of care, the initial time and energy the *Kmihqitahasultipon Program* devoted to designing its system of care continues to profoundly impact delivery of services. Four weeks afford the opportunity for attention to and deliberation of critical issues for any system of care committed to family-centered services, an opportunity that rarely exists in the day-to-day demands of providing children's mental health services. As Marjorie Withers, clinical supervisor at the *Kmihqitahasultipon Program*, commented, the training program "joined people in their hearts as well as in their conceptual frameworks."

Family-provider collaboration at systems of care requires a commitment of time and energy that allows for difficult conversations on vision and goals, and on how to respect diverse community values and cultural realities. Family-provider collaboration requires space for conflict; attention to differences in opinions, assumptions, and expectations; a willingness to take risks and be vulnerable; and a willingness to change deep-seated ideas and practices about children's mental health services. The *Kmihqitahasultipon Program* training, in its four week, all day structure, offered space for conflict, difference, risk and change. None of these are likely to occur or surface when people are in a hurry or pressed on by a too-short meeting time. The *Kmihqitahasultipon Program* training program is a model one site chose to engage as a commitment to family-centered children's mental health services in their community, and is a promising practice that offers insight into programs that support family-provider collaboration. As the staff at the *Kmihqitahasultipon Program* stressed, their services are based on the idea that to nurture a community, mental health services site staff must be able to nurture themselves.

## **SAN MATEO COUNTY MENTAL HEALTH, FAMILY PARTNERSHIP TEAM, CALIFORNIA<sup>1</sup>**

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### **Promising Practice**

Use of strengths-based assessment by family members when working with managers, administrators, supervisors, and other staff.

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San Mateo County's system of care has evolved over many years of development and financial support from both the state and federal levels. In 1986, California legislative action AB3632 made it possible for children in special education programs to receive mental health services. In 1989, the county received a grant to implement a cost containing interagency system of mental health care for children with serious emotional disorders and their families that would reflect AB377, a state legislative initiative. In 1994, San Mateo County, along with four other California counties, received Federal funding from Center for Mental Health Services to expand the array of services for children with serious emotional disturbances and their families. In 1995, the county received a grant via a state funded pilot program designed to prevent non-public school placements for special education children who have serious emotional disorders.

The San Mateo Mental Health Division annually signs interagency memoranda of understanding with Juvenile Probation, Child Welfare and Education. Interagency collaboration occurs via formal and informal structures and practices. Specialized Mental Health teams are co-housed with Juvenile Probation, Child Welfare, and Education to serve children and youth in those subsystems. The *Family Partnership Team (FPT)*, a specialized Mental Health team, was created in the fall of 1994. The *Family Partnership Team's* directive is "to ensure that families are involved at every level of the system of care." A major function of the *Family Partnership Team* is to bridge families with needed system of care services. This profile will address tokenism and the role of the *Family Partnership Team* to reduce and eliminate it.

### **Strategies to Overcome the Existence and Tolerance of Tokenism**

The *Family Partnership Team* is committed to zero tolerance of tokenism. In developing strategies to improve communication and understanding, the *Family Partnership Team* utilizes a strengths-based approach toward system of care providers and policy makers. Family members are taught, then

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<sup>1</sup> Delia McGrath, Family Partnership Coordinator at Central County Mental Health, made significant writing contributions to this profile.

encouraged and supported to assess the strengths providers and policy makers bring to the work of collaboration. Strengths assessment is rigorously applied to managers, administrators, supervisors, and line staff throughout the system of care.

Building on strengths that have been identified, the *Family Partnership Team* works closely with the providers and policy makers to achieve the desired outcomes of helping families succeed. The *Family Partnership Team* asks the policy makers, managers or direct service providers how they see the families' needs and goals integrated with their own. The *Family Partnership Team* may also ask the staff members or policy makers if they can count on their partnership and support to find common solutions. In this way, the providers or policy makers act as resources for the *Family Partnership Team* and, hopefully, they are simultaneously gaining insight into the importance of collaboration with families, and are treating families with respect and dignity.

Another strategy selected by the *Family Partnership Team* to eliminate tokenism is to help family members become competent with organizational structures, technical language, and formal and informal decision making processes of the system of care and its major subsystems. The effectiveness of family involvement on policy and advisory committees is largely contingent on the family members' capacities to understand what is being discussed. When possible, family members are assigned to macro-level committees in pairs to strengthen their representation of the family perspective and to decrease their sense of isolation.

## **SANTA CRUZ COUNTY CHILDREN'S MENTAL HEALTH, FAMILY ADVISORY COUNCIL, CALIFORNIA**

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### **Promising Practice**

Utilization of two documents that affirm value of family-provider collaboration, *Memorandum of Understanding* and Family Partnership Master Plan.

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Santa Cruz County began receiving Center for Mental Health Services funding in 1994. State legislation and funding as early as 1989 was specifically directed at development of the existing system of care. The primary population the Santa Cruz system of care serves are children and youth with serious emotional disorders who are currently in, or at risk of, out-of-home placement. Services offered include outpatient day treatment, case management, crisis, short-term group home, respite, intensive family support, and various forms of wraparound support.

In seeking out avenues for family participation in the system of care, a staff person with community organizing skills recruited and trained parents as partners, and in turn, parent leaders emerged from this

process. The staff person then identified a core of six to seven parents who formed the Family Advisory Council. In time, it became clear that families were committed to providing their own leadership, rather than communicating with the site through a provider. Families decided they were interested in direct communication with families, and in contributing to a family presence in mental health clinics in the county.

## **Achieving Trust and Reducing Suspicion**

Two particularly useful resources for achieving trust and reducing suspicion Santa Cruz has developed at their site include the “Memorandum of Understanding” and the Family Partnership Master Plan. Both documents lend support to family-collaboration.

The “Memorandum of Understanding” affirms the value of family-provider collaboration to children’s mental health. In particular, it acknowledges the importance of family-provider collaboration to every level of the system of care, including policy and program development and working relationships. The site asks each team member to read and sign this document as a confirmation of their commitment to family-provider collaboration.

Agency staff as well as families and community members created the Family Partnership Master Plan. This plan provides guidelines for the objectives, roles and responsibilities in family-provider partnership, and is often useful in the case of conflict or disagreement. Finally, this plan acts as a gauge with which to view family-provider collaboration.

In developing and implementing the Memorandum of Understanding and the Family Partnership Master Plan, providers and families in Santa Cruz learned several lessons pertinent to family-provider collaboration. First, collaboration is a skill that must be learned, by both providers and family members. Also, the vision of the organization must leave room for differences among participants in the system of care. Families and providers also realized that even when a Memorandum of Understanding and a Family Partnership Master Plan exist, commitment to collaboration, for both providers and family members, may be inconsistent or uneven. To support an ongoing commitment to family-provider collaboration at all levels of the system of care, it is important that family members have a strong presence at all clinic sites (and at key meetings at each site), and that systems of care compensate family members for their work.

## STARK COUNTY FAMILY COUNCIL, STARK COUNTY, OHIO<sup>2</sup>

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### Promising Practice

Ongoing, interactive, and accessible training at all levels for all participants in the system of care.

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## Background

*Stark County Family Council* began providing services to children and families in the mid-1980s in response to a state-mandated effort to establish interagency structures that would meet particular needs of children and families. In 1993, a Center for Mental Health Services grant was awarded to Ohio and split between the *Stark County Family Council* and the *Southern Ohio Consortium*.

*Stark County Family Council's* (SCFC) governance is through a Board of Trustees, which includes:

- *Seventeen executive-level representatives from the public systems and agencies serving children:* child welfare, mental health, schools, family court, mental retardation/developmental disabilities, health, substance abuse, Head Start, early intervention, and youth services;
- *Six family representatives:* recruited and trained by Families and Communities Equal Success (FACES) of Stark County, a family support organization working in collaboration with the many family advocacy and support organizations in the county; and
- *Ten community representatives:* faith community, area foundations, youth representation, United Way, and geographic representation.

The Community Mental Health Board (CMHB), a part of the Ohio Department of Mental Health, contracts to a variety of agencies to provide mental health services and support for families. Through the CMHB, *Stark County Family Council* is contracted to administer the community infrastructure program of the grants, while Child and Adolescent (C&A) is contracted to provide direct services. Within the Stark County system of care, ACCORD acts as clinical review and payor, managing pooled funds from eight agencies represented on the Board of Trustees.

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<sup>2</sup> Carol Lichtenwalter, Director, Stark County Family council, and her colleagues, made significant writing contributions to this profile.

The initial target population for services focused on youth with the most significant needs and with multi-agency involvement. That target has expanded, and now includes children and families who are having difficulty receiving services to meet their needs. Children are referred by all participating agencies, and primarily through case management, teachers and counselors, as well as through *FACES*.

The *Stark County Family Council* provides and funds a variety of services. *Stark County Family Council* contracts with *FACES* for flexible services such as family advocacy, respite care, and other supportive services. Child and Adolescent provides more traditional counseling services as well as case management, in-home counseling and support, respite care, a youth mentoring program, and a peer mentorship group.

The *Stark County Family Council* has also created a variety of community wraparound services within public agencies and schools. For example, Creative Community Options (CCO) meetings are held to develop wraparound plans for struggling youth and their families. When families participate in a CCO process, they are automatically connected with a family advocate who has been trained on the wide variety of community services available to families. Family advocates act as liaisons between the case manager and the family, distributing wraparound plans and following up with families and service providers to ensure that the plan is being implemented.

## **In Response to the Challenge of Incomplete and Uneven Training**

Training in Stark County is ongoing, interactive, covers all areas of services, and addresses both formal and informal strategies for effective services and family support. Formal, cross-system trainings occur consistently throughout the year and include professionals, paraprofessionals, family advocates, school personnel, case managers, and family support workers. This training forms the basis for family-provider collaboration across all child and family serving systems and agencies.

A portion of the *Stark County Family Council* web site is dedicated to a Training Locator, which is an interactive database of the many training opportunities available throughout the system of care. In addition to this, a *Stark County Family Council* community planning team identified several areas in which training would be useful, particularly for paraprofessionals and family advocates. These roles include case management, advocate, home visitor, and family support worker. The *Stark County Family Council* coordinates a list of training possibilities and resources, and develops and implements their own training programs. This list serves as a highly relevant and useful compilation of trainings in support of family participation and family-provider collaboration.

## PROJECT HEARTBEAT, SAN DIEGO, CALIFORNIA<sup>3</sup>

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### Promising Practice

Strong support of family participation in conferences and within county mental health services; strong support from county for family organization.

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## Background and Overview

The creation and implementation of the Heartbeat System of Care is coordinated by *Project Heartbeat* of the San Diego County Bar Association. With an initial grant from the Annie E. Casey Foundation, *Project Heartbeat* began to facilitate a partnership between: 1) the family sector (including youth); 2) the public sector (including the schools and the Departments of Probation, Mental Health, and Social Services); and 3) the private sector (including all private providers of these services to children and families). These three constituencies are responsible for designing the system of care. Since this initial grant, the County of San Diego and *Heartbeat* were awarded a five-year start up grant from the Center for Mental Health Services (part of the Substance Abuse Mental Health Services Administration) to fund the fundamental and initial steps of the implementation of the Heartbeat System of Care. This profile will focus on the development of the family organization, as well as on the three-sector design within the service system.

## The Three-Sector System of Representation

The *Heartbeat Project's* system of care emphasizes early intervention; family-centered, neighborhood-based services; and keeping children close to home. The target population includes youth with serious emotional disturbances, and the project places a high priority on services that are accessible to all youth within the target population. Families United, the Heartbeat Family Organization, began taking shape in October 1996. In addition to having held two annual conferences, the family organization meets monthly.

Since its inception, *Project Heartbeat* has vigorously held family participation as a guiding principle. The cornerstone of *Heartbeat* is the philosophy and practice of a three-sector partnership between public agencies, private providers and youth and family representatives. This concept was established long before San Diego was awarded the Center for Mental Health Services service site grant. Accountability and

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<sup>3</sup> Liz Maruchau, Heartbeat Liaison, made significant writing contributions to this profile.



responsibility are built in at every level of the *Heartbeat* initiative, as any imbalance by one sector may be identified by other sectors. This three-sector relationship is inherent in the oversight committee known as the Heartbeat Consortium. The Consortium is comprised of equal numbers of public, private and family public agencies and of private sector and family and youth organizations. The Consortium reviews and considers documents that will either be forwarded to the Board of Supervisors (or other government bodies, such as school boards) for approval or returned to the *Heartbeat* staffing group for further review and development. The Consortium members speak on behalf of their constituency of interest. *Project Heartbeat* developed specific strategies in order to fulfill the vision of families becoming true partners at all levels of the system redesign. Ideally, as the family organization grows and recruits new members, there will be equal representation on every committee.

## **Developing a Family Organization**

A substantial portion of the grant from the Annie E. Casey Foundation was devoted to supporting families and their role in the system of care. The first strategy for organizing families was a conference held in October 1996, which brought together 104 family members. The conference focused on how services could be improved to better meet the needs of children and families in San Diego County. The conference successfully provided the opportunity for the inception of a family advocacy organization. The vision for this family organization was to ensure a continuing voice for parents in the design, oversight and provision of services for families caring for troubled youth.

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*The vision for this family organization was to ensure continuing voice for parents in the design, oversight and provision of services for families caring for troubled youth.*

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As a result of this conference, several family members were recruited to participate in the *Heartbeat* community forum referred to as the “Charrette,” held in April 1997. The Charrette was designed to bring together the three “sectors” essential to the success of building a new system of care (public, private and family sectors). The common themes that families identified at their conference were brought forth by family members with a unified voice in the Charrette. The outcome of *Heartbeat*’s Charrette was phenomenal. Over 200 well-informed, skilled people from the three sectors in the San Diego community gathered together for two-and-a-half days to design the blueprints for a new system of care serving children with serious emotional disturbances. It was historic in and of itself to have equal representation of each sector at *Heartbeat*’s first forum.

Understanding the need to further facilitate the organizing process, *Project Heartbeat* received grants from the California Endowment and the Annie E. Casey Foundation to hire a full time Families United Coordinator and a full time Families United Developer. *Project Heartbeat* enhanced the public-private

partnership by employing a part-time licensed clinical social worker to support the development of the family organization (This staff person was reassigned from county mental health services). After the family conference, family members began to meet monthly to develop a strong and unified family/youth voice,

which eventually was the impetus for establishing Heartbeat Families United.

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*The second conference was entirely planned, organized and staffed by family and youth members. This accomplishment transformed Heartbeat Families United from being a task force to a fledgling family advocacy organization.*

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In October of 1997, Heartbeat Families United held their second annual Family Conference and increased their membership to over 175 people. The second conference was entirely planned, organized and staffed by family and youth members. This accomplishment transformed Heartbeat Families United from being a task force to a fledgling family advocacy

organization. This was strongly reflected in the conference's theme, which focused on establishing a unified family organization to ensure that children received effective services. The conference inspired enthusiasm, provided new knowledge, increased trust, and reinforced the vision of families participating in Heartbeat's policy, decision making, and oversight. Most importantly, it led to the development of the Families United Steering Committee. In addition the conference also motivated members to do outreach to increase family membership, to create an orientation packet for new members, as well as to create a Families United brochure. Family member representation increased on all of the *Heartbeat* committees.

The evolution of family participation has continued in *Project Heartbeat*. Since January 1997, the policy and design group for the *Heartbeat* system of care, which meets on a weekly basis, has included family participants. Heartbeat Families United became a chapter of the Federation of Families for Children's Mental Health in April of 1998. Families United provides a monthly support group for parents and a monthly presentation on topics pertaining to families with children who have serious emotional disturbances.

## **FAMILIES REACHING IN EVER NEW DIRECTIONS (F.R.I.E.N.D.S.), MOTT HAVEN, NEW YORK**

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### **Promising Practice**

Broad spectrum of families who participate in system of care;  
participation of families at all levels of system of care

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### **Overview**

The New York State Office of Mental Health was awarded a Center for Mental Health Services grant in 1994 and *Families Reaching in Ever New Directions (F.R.I.E.N.D.S.)* began serving children and their families in April 1996. This initiative is a research based and family-driven integrated system of care, serving the mental health needs of children with serious emotional disorders and their families, in the South Bronx district known as Mott Haven. The site focuses on children with serious emotional disorders who are also in the child welfare system and is one of two managed care demonstrations in the state of New York.

The planning and development of *F.R.I.E.N.D.S.* has, from the beginning, exhibited a strong commitment to family participation. Family members represent 51 percent of the membership on the Planning Board; *F.R.I.E.N.D.S.* employs family members as community linkage workers, family advocates and family research assistants. Direct care providers are contractually obligated to follow family involvement guidelines. The consumers at *F.R.I.E.N.D.S.* strongly represent the diverse population of Mott Haven with the majority of children and families being of Puerto Rican and Dominican heritage and the second largest group being African American.

### **Reflecting Diverse Community Values**

Reflecting diverse community values and norms is in part accomplished through family participation at all levels in the system of care. The *F.R.I.E.N.D.S.* mission statement requires that family members have 51 percent representation on all decision making bodies at all levels of the organization. At the system level, there are stipended parent representatives on the Board of Directors who work with other Board members to plan and implement new programs. Family representatives also serve on individual subcommittees and work groups where they are responsible for carrying out various objectives of the project. Family representatives participate in interviewing applicants, selecting service providers and hiring staff members for *F.R.I.E.N.D.S.* Six family members are employed by *F.R.I.E.N.D.S.* as family research assistants. They are located at the *F.R.I.E.N.D.S.* office with other staff members, two of whom have children currently

receiving services. Parent research assistants and Quality Improvement Team members identify successful and problematic methods of collecting evaluation data and are responsible for implementing the project's evaluation plan. Quality Improvement Team members also respond to the results of surveys that collect information from families about their experiences and satisfaction with service delivery and within the system of care.

Families are encouraged to participate in the monthly Family Support Forums where family advocates from all of the child-serving agencies gather to exchange information and resources available in the community. In addition, there is a Family Learning Circle that provides families with opportunities for ongoing education and training. These meetings encourage families to learn about *F.R.I.E.N.D.S.*' services and opportunities for the family to participate in the process. Meetings are held in the community at convenient times and with transportation available.

### **Support for Family Participation in F.R.I.E.N.D.S.**

#### **Circle of Learning**

A one-day orientation for anyone wishing to know more about the project.

#### **Family Learning Circle**

The education and information meeting for family members participating in work-groups, committees and decision-making bodies of the project.

#### **Among F.R.I.E.N.D.S.**

This is the workgroup of the Family Learning Circle.

#### **Family Support Forum**

Parent Advocates and community activists/leaders from the four major child-serving systems of Education, Juvenile Justice, Child Welfare and Mental Health meet to collaborate on promoting appropriate service delivery practices.

#### **F.R.I.E.N.D.S. Pen Pal Club**

Members of this group participate in letter and gift exchanges, conference calls and cultural learning labs with project sites similar to F.R.I.E.N.D.S.

Although families have a strong voice in many areas of *F.R.I.E.N.D.S.*, some challenges still exist. Family input is highly valued by provider staff at the local level, but is not equally valued by individuals at other levels of the mental health system or in other service sectors. Continuing attention to family members' feedback, perhaps through the Quality Improvement Team, will result in additional modifications to the range and kind of therapeutic interventions available. Minty noted that finding and providing culturally

appropriate treatment responses and family support is one of the more critical aspects of developing a system of care that is responsive to the community. She feels that the family members involved in *F.R.I.E.N.D.S.* have witnessed the organization's ongoing commitment to collaboration and to improving services to families and children and their openness to ongoing dialogue. This is supportive to continuous and creative family-provider collaboration.

## **SOUTH PHILADELPHIA FAMILY PARTNERSHIP PROJECT**

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### **Promising Practice**

Summer Day Camp, which offers community-based, culturally competent services for children with serious emotional disturbances, and which is in part designed and staffed by family members.

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The *South Philadelphia Family Partnership (SPFP)* Project began receiving Center for Mental Health Services grant funds in 1994. The *South Philadelphia Family Partnership Project* currently works with a broad array of partner-agencies in providing services and is administered through the Children's Mental Health Services Unit of the Office of Mental Health and Mental Retardation. This profile will focus on a summer camp program that the South Philadelphia Family Partnership Project offers annually in cooperation with other community agencies. During its history, the camp has developed from an experience for South Philadelphia children living in kinship care, to a program which focuses on neighborhood children with serious emotional disturbances, including but not limited to, children living in kinship care. All of the children attending the camp last summer (1998) were experiencing emotional or mental health problems. The summer camp has been particularly instrumental in supporting new roles and relationships for family members and providers, in providing creative possibilities for sustainability, and in responding to diverse community values and norms.

The *South Philadelphia Family Partnership Project* works with children who have a serious emotional disorder. In addition to residing in the service area of nine South Philadelphia schools (all of which receive services offered through the *South Philadelphia Family Partnership Project*), children must have a diagnosis from the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), be receiving services from the mental health system or other child-serving agencies, and be identified as in need of mental health services. South Philadelphia has approximately 150,000 residents, 37,000 of whom are under 18 years of age; about half of the population is white, 37 percent are African American, 5 percent are Asian American, 2 percent are Latin American, and less than 1 percent are Native American.

The *South Philadelphia Family Partnership Project* works closely with several institutions and agencies. A significant partner is the School District of Philadelphia. Many services are offered at the schools, and each school has a School Community Team Coordinator (Family members hold these *South Philadelphia Family Partnership Project* staff positions). Additional partner agencies include Citizens Acting Together Can Help (CATCH), a mental health agency; Eighteenth Street Development/Raising Others' Children (ROC), a kinship care support organization; Parents Involved Network (PIN), the statewide family organization; and the Mayor's Office of Family Centers. Secondary partners to the *South Philadelphia Family Partnership Project* include several state and city-level government agencies.

As part of the grant implementation, the *South Philadelphia Family Partnership Project* articulated its commitment to working with families and children as the foundation of the system of care, rather than working with families and children only as “recipients” or “consumers” of care. Family members work as family advocates at the local Family Centers (two positions), as family advocates within the South Philadelphia Family Partnership Project (two positions), and as the school/community team coordinators (three positions). In conversations with family members involved with the *South Philadelphia Family Partnership Project*, family advocates affirm that key staff in the Children's Mental Health Unit and in the Office of Mental Health and Mental Retardation “want nothing but the best for families.” At the same time, family members, in the words of a *South Philadelphia Family Partnership Project* family advocate, “always live with a different bottom line” than do providers.

*Family advocates affirm that key staff ‘want nothing but the best for families.’ At the same time, family members, in the words of a SPFP Project family advocate, ‘always live with a different bottom line’ than do providers.*

In the *South Philadelphia Family Partnership Project*, collaboration occurs because families are persistent in their articulation of the “bottom line,” and because of the support for families from the Children's Mental Health Services Unit Office.

## **The Youth Advocate Program Summer Day Camp**

The summer day camp is in its seventh year. This is the first year it was offered through the Philadelphia Youth Advocate Program. In previous years, it was a program of Raising Others' Children. The camp operates within a therapeutic framework, and offers community-based, culturally competent services for children with serious emotional disturbances. The camp operates in the community in which most of the children live. The camp specifically aims its services at low-income African American, Caucasian, and Asian American families.

The Philadelphia Youth Advocate Program summer camp is for children from 5 to 12 years of age, runs for five weeks in July and August, and operates Monday through Friday from 8:30 am until 2:30 pm. Philadelphia Youth Advocate Program summer camp has five primary objectives:

- to provide a summer camp at no cost to families;
- to provide opportunities for children with serious emotional or mental health issues so that they may develop a positive self-image;
- to provide opportunities for children with serious emotional or mental health problems to develop positive interpersonal skills;
- to provide caregivers/family members with strategies for initiating and maintaining positive, supervised activities with children at home; and
- to provide much needed respite to families of children with mental illness.

The camp draws on various forms of artistic expression, such as visual arts, vocal arts, and dance, to support development of skills for interpersonal relationships, daily decision making, and problem solving. A total of 19 paid full-time employees and 8 paid part-time employees staff the camp.

## **Philadelphia Youth Advocate Program Summer Camp and Family-Provider Collaboration**

The Philadelphia Youth Advocate Program summer camp has supported family-provider collaboration by offering an accessible, community-based, culturally competent program that is designed and partially staffed by family members. The camp provides continuation of mental health care for children in the local community, and also establishes an ongoing program within the system of care for which family members have primary leadership and responsibility. Finally, as *South Philadelphia Family Partnership* approaches the end of Center for Mental Health Services funding, the camp is now funded outside of Center for Mental Health Services resources. The Philadelphia Youth Advocate Program summer camp demonstrates promising practices in family-provider collaboration particularly in the areas of new roles and relationships for families and providers, sustainability, and respect for diverse community values and norms.

### **New Roles and Relationships for Families and Providers**

The summer camp became a regular component of the *South Philadelphia Family Partnership Project* largely at the initiation of parents, who clearly articulated the need for ongoing care for children during the summer months. As *South Philadelphia Family Partnership Project* staff began to look at possible



providers for the camp, it became clear that family members did not want one of the primary providers of services for children in the *South Philadelphia Family Partnership Project* to administer the camp. In seeking out a mental health care provider for the camp, a primary criteria for *South Philadelphia Family Partnership Project* staff was that the provider contracted to administer the camp valued family leadership. When families indicated their interest in a provider that was at that time not credentialed by the local behavior managed care organization, the *South Philadelphia Family Partnership Project* staff made a commitment to support Philadelphia Youth Advocate Program through the credentialing process.

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*In working toward family-provider collaboration, one particularly strong benefit of the camp has been the opportunity it offers for families to assume roles of leadership and responsibility.*

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The result of this commitment is a family-driven, designed, and staffed summer day camp offering children's mental health services. Families are actively involved in the process of recruiting children for the camp. The duration and daily schedule of the camp also provides families with positive interactions with mental health services, an agency with which many families may have had negative experiences. In working toward family-provider collaboration, one particularly strong benefit of the camp has been the opportunity it offers for families to assume roles of leadership and responsibility.

## **Sustainability**

For the first three years, the summer camp was primarily funded by the Center for Mental Health Services grant. Now in its seventh year, the camp is a therapeutic summer camp funded through the local Medicaid behavioral managed-care organization. This year, all of the children attending the camp were receiving mental health services prior to the summer camp. While Center for Mental Health Services funding was necessary for initiating and establishing the summer camp and the delivery of mental health services through the camp, sustainability has been achieved. As previously mentioned, the *South Philadelphia Family Partnership Project* staff agreed to work with a family-chosen provider that was initially noncredentialed, and to support them through the credentialing process.

## **Respect for Diverse Community Values and Norms**

Philadelphia Youth Advocate Program summer camp is primarily aimed at a local neighborhood community that includes nine schools. Retaining a community-based focus enables designers of the camp to offer mental health care particularly well-suited to the children the camp serves. The camp's primary objectives for children include the development of a positive self-image, interpersonal skills, conflict

resolution abilities, and alternative artistic outlets for positively expressing emotions. The skills are immediately relevant to children in the South Philadelphia community, many of whom have witnessed violence, have been a victim of abuse, or have had to cope with the loss of a parent through death or incarceration.

The summer camp also places a high value on increased awareness of campers' cultural identities. This summer's theme, "Arts and Attitudes. . .A Summer of Singin' and Swingin'," uses music, dance, singing, and other art forms to provide a therapeutic framework in which children work with culturally relevant art forms to improve social, emotional, cognitive, and physical behaviors. In addition to composing, conducting, directing, performing their own musical and dramatic productions, and developing skills in applied arts, campers visited several art and theater sites (including StepAfrika, American Theater Arts for Youth, and the Seaport Family Theatre), and interacted with elders in music, dance, and theater careers. Using art, music, and dance, and culturally appropriate art forms, and providing children with the opportunities to examine their emotions, reactions, and responses to daily life experiences, offers a model of children's mental health services that is community-based and meaningful in immediate ways.

## **Conclusion**

The Philadelphia Youth Advocate Program Summer Day Camp is an example of a promising practice in children's mental health that supports family-provider collaboration at a variety of levels. Offering children in South Philadelphia mental health care on a regular basis during the summer months, the camp affords opportunities for family leadership, demonstrates a process of achieving sustainability, and delivers children's mental health services that are directed to the particular needs and backgrounds of children in the South Philadelphia community.

## **WRAPAROUND MILWAUKEE**

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### **Promising Practice**

Development of mission statement for system of care with significant input from family members.

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In 1990, the state of Wisconsin awarded Milwaukee County with a “Children Come First” grant to develop a system of care. This grant was used to fund efforts within the Child and Adolescent Services Division and the county’s mental health agency, and to implement intensive in-home and case management services. In 1994, the Center for Mental Health Services awarded grant funds to Milwaukee to support a wraparound model of care designed to meet the full spectrum of families’ needs, and to achieve positive planned outcomes.

Wraparound Milwaukee is a managed care organization that utilizes funds from mental health, child welfare, and Juvenile Justice agencies. The project is administered through the Children’s Mental Health Division, which is a part of the Milwaukee County Human Services Department. The project director and project management staff are employed by the Child and Adolescent Services Branch of Milwaukee County Mental Health Division. Family participation at the systems level is channeled through the involvement of a new family advocate organization called Milwaukee County Mental Health. Parent advocates offer services to families throughout the system of care.

## **Response to the Challenge of Vision and Goals**

This profile will speak to the challenge of shared vision and goals. The current family organization was initiated approximately three years ago. Since then, Margaret Jefferson, Milwaukee Wraparound Family Advocate, and several family members, with the support of site director Bruce Kamradt, developed a mission statement that reflects the vision and goals of Milwaukee County Mental Health Family Advocates.

Through the process of developing a family organization, as well as through a specific commitment to vision and goals, family advocates involved with Wraparound Milwaukee gained insights directly related to family-provider collaboration. As Margaret Jefferson stated, time and perseverance were crucial components in articulating family-centered vision and goals. Continuous support on the part of the site director was also critical to their work. In order to gather input from a broad range of families regarding vision and goals and the mission statement, it became clear that family advocates would need to: (1) seek out families who were excited about

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*Continuous support  
on the part of the site  
director was also  
critical to their work.*

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(or at least willing) to contribute to the process; (2) create an informal and comfortable environment in which to talk with families; and (3) to draw on common interests and concerns. The mission statement became one component of the system of care in which family members had significant input.

# References

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- Adams, J., Biss, C., Burrell Mohammad, Meyers, J., and Slaton, E. 1997. *Family-professional relationships: moving forward together*. National Peer Technical Assistance Network.
- Allen, Reva I. and Christopher G. Petr. 1998. Rethinking family-centered practice. *American Journal of Orthopsychiatry*, 68 (January): 4-15.
- Bishop, Kathleen Kirk, Mary Skidmore Taylor, and Polly Arango, ed. 1997. *Partnerships at work: lessons learned from programs and practices of families, professionals and communities*. Burlington, Vermont: University of Vermont.
- Bryant-Comstock, Scott, Barbara Huff, and John VanDenBerg. 1996. The evolution of the family advocacy movement. Chapter 19 of *Children's mental health: creating systems of care in a changing society*. Baltimore: Paul H. Brookes Publishing Company.
- Cohen, Robert and Christopher Lavach. 1995. Strengthening partnerships between families and service providers. In *Reinventing human services: community- and family-centered practice*. New York: Aldine de Gruyter.
- Delia McGrath, Family Partnership Coordinator at Central County Mental Health, made significant writing contributions to this profile.
- DeChillo, Neal. 1993. Collaboration between social workers and families of patients with mental illness. *Families in Society: The Journal of Contemporary Human Services*, February: 104-115.
- DeChillo, Neal, Paul E. Koren, and Kathryn H. Schultze. 1994. From paternalism to partnership: Family and professional collaboration in children's mental health. *American Journal of Orthopsychiatry* 64 (October): 564-576.
- DeChillo, Neal, Paul E. Koren, and Margaret Mezera. 1996. Families and professionals in partnership. Chapter 21 of *Children's mental health: Creating systems of care in a changing society*. Baltimore: Paul H. Brookes Publishing Company.
- Friesen, Barbara J. and Barbara Huff. 1990. Parents and professionals as advocacy partners. *Preventing School Failure* 34 (Spring): 31-35.
- Friesen, Barbara J., Paul Koren, and Nancy Koroloff. 1992. How parents view professional behaviors: A cross-professional analysis. *Journal of Child and Family Studies* 1: 209-231.
- Friesen, Barbara J. and Nancy M. Koroloff. 1990. Family-centered services: Implications for mental health administration and research. *The Journal of Mental Health Administration* 17 (Spring): 13-25.

- Friesen, Barbara J. 1996. Family support in child and adult mental health. In *Redefining family support: Innovations in public-private partnerships*. Baltimore: Paul H. Brookes Publishing Co.
- Friesen, Barbara, and Kathryn Schultze. 1992. *Parent-professional collaboration content in professional education programs: A research report*. Portland, OR: Research and Training Center on Family Support and Children's Mental Health, Portland State University.
- Hanley, Jerome H. and Harry H. Wright. 1995. Child mental health professionals: The missing link in child mental health reform. *Journal of Child and Family Studies* 4 (December): 383-388.
- Huff, Barbara, Dixie Jordan, Jane Adams, Richard Donner, William Reay, and Charlie Biss. 1998. Conference presentation packet: "Developing Family-Professional Partnerships." Training Institutes: Developing Local Systems of Care in a Managed Care Environment. Orlando, Florida.
- Johnson, Harriette C. et al. 1988. Social workers' views of parents of children with mental and emotional disabilities. *Families in Society: The Journal of Contemporary Human Services*, (March-April): 173-187.
- Jivanjee, Pauline R. and Barbara J. Friesen, eds. 1994. *Building on family strengths: research, advocacy and partnership in support of children and their families. 1994 conference proceedings*. Portland, OR: Research and Training Center on Family Support and Children's Mental Health, Portland State University.
- Jivanjee, Pauline R. and Barbara J. Friesen. 1997. Shared expertise: Family participation in interprofessional training. *Journal of Emotional and Behavioral Disorders* 5 (Winter): 205-211.
- Koren, Paul E., Robert I. Paulson, Ronald F. Kinney, Diane K. Yatchmenoff, Lynwood J. Gordon, and Neal DeChillo. 1997. Service coordination in children's mental health: An empirical study from the caregiver's perspective. *Journal of Emotional and Behavioral Disorders* 5 (Fall): 162-172.
- Koroloff, Nancy M., Barbara J. Friesen, Linda Reilly, and Judy Rinkin. 1996. The role of family members in systems of care. Chapter 22 of *Children and mental health: Creating systems of care in a changing society*. Baltimore: Paul H. Brooks Publishing.
- Koroloff, Nancy M. and Barbara J. Friesen. 1997. Challenges in conducting family-centered mental health services research. *Journal of Emotional and Behavioral Disorders* 5 (Fall): 130-137.
- Koroloff, Nancy M. and Harold E. Briggs. 1996. The life cycle of family advocacy organizations. *Administration in Social Work* 20: 23-42.
- Koroloff, Nancy, Richard Hunter and Lynwood Gordon. 1995. *Family involvement in policy making: A final report on the families in action project*. Portland, OR: Portland State University, Research and Training Center on Family Support and Children's Mental Health.

- VanDenBerg, John E. 1992. Individualized Services for Children. *New Directions for Mental Health Services* 54 (Summer).
- Wahl, Otto F. 1989. Schizophrenogenic parenting in abnormal psychology textbooks. *Teaching of Psychology* 16 (February): 31-33.
- Williams-Murphy, Tracy, Neal DeChillo, Paul Koren, and Richard Hunter. 1994. *Family/professional collaboration: The perspective of those who have tried*. Portland, OR: Portland State University, Research and Training Center on Family Support and Children's Mental Health.





# APPENDICES



# Appendix A

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## DESCRIPTION OF CHALLENGES TO FAMILY-PROVIDER COLLABORATION

The monograph on *Promising Practices in Family-Provider Collaboration* identifies sites that have successfully responded to particular challenges in family-provider collaboration. As a first step in identifying promising practices, we spoke with family coordinators and site directors at the Center for Mental Health Services grant sites about challenges you have faced in family-provider collaboration. Following our conversations, we identified two broad groups of challenges.

At one level, comments from site directors and family coordinators demonstrated that challenges to family-provider collaboration are directly linked to:

- a low commitment and respect for the participation of family members in the system of care; and
- a lack of agreement among family members and providers on how collaboration is defined and practiced at a site, and more particularly, agreement on how power is shared.

At a second level, the two primary challenges noted above resulted in numerous secondary challenges:

- ***Achieving trust and reducing suspicion among providers and family members.*** Family members and providers bring with them assumptions and past experiences in connection with mental health services. Many providers question the value of family participation, and the credibility and objectives of family members. Family members must discern if and how providers value their participation.
- ***Incomplete or uneven training on issues related to family-provider collaboration.*** Training for family members and providers that: (1) articulates the benefits of families to the system of care, (2) familiarizes families with the agency with which they are working and (3) supports family-provider collaboration. Such training is often non-existent, too short, only scratches the surface, and/or does not adequately address the value of family participation in the system of care.
- ***Lack of conversation and/or consensus concerning vision and goals.*** Setting priorities is difficult for any organization. Reaching consensus on vision and goals becomes more difficult when family members and/or providers wrongly assume common vision and goals, and/or when the providers do not value family

participation. When the family organization is one that is autonomous from the site, the priorities of the site may be different from or in conflict with those of family members.

- ***Difficulty of sustaining new roles and relationships among family members and providers.*** In spite of increased acknowledgment that families are valuable participants at all levels in the system of care, the long-standing framework representing providers as the solution and families as the problem continues to exist. When it comes to day-to-day decisions and interactions, many questions and conflicts remain. For example, when hard decisions are required, it can be more convenient and expedient to resort to hierarchical decision making processes than it is to change the decision making structures. For some of you, collaboration requires coming together as “equals;” others question the meaning and desirability of working as “equals.” Unlearning old habits and learning new practices requires self-examination and a willingness to be vulnerable, risks few are willing to take publicly.
- ***Lack of support for family participation on the part of other service systems.*** Family-provider collaboration is impacted when related service systems have yet to value family participation. Often service systems outside of the mental health system of care view family participation as a burden, reject efforts to involve families, are reluctant to talk with family members, and are disrespectful toward family members in meetings. Some of the providers we spoke with find it critical to intervene when individuals from other agencies act disrespectfully toward families.
- ***Achieving sustainability of the family organization following the grant.*** This challenge is particularly dependent on the history of the family organization in the community, on local and state funding of family organizations in the system of care, and on the value the site places on the ongoing existence of the family organization.
- ***Concerns regarding confidentiality.*** Providers often raise the issue of confidentiality. Confidentiality becomes an issue in deciding how information is shared with family members employed by the site, in connection with legal guidelines and requirements, and in regard to family participation at varying levels of the system of care. Several of you stated that these concerns are frequently based on an assumption (that the family member will speak inappropriately) rather than an actual occurrence. Confidentiality also becomes an issue in individual cases when a family member and provider disagree on how much information about the family will be shared with other agencies.
- ***Imbalance of power related to financial decisions.*** This challenge most often concerns family members. Allocation of funding to the family organization raises issues including inadequate money given to the family organization for what the site/

agency expects the family organization to do; the difficulty of being creative and innovative when family organizations depend on the site/agency for their existence; and the reality that there are often strings attached to the money the family organization does receive.

- ***Reflecting diverse community values and norms in the system of care.*** Family participation in systems of care is in part related to the extent to which the existing system of care reflects the values, beliefs, and norms of the community it serves. If structures within the system of care are disrespectful of families' priorities and understandings of care and mental health, this discourages collaboration. Systems of care which have been organized around families' norms and with the participation of families throughout the development process are much more likely to be supportive of collaboration.
- ***Existence and tolerance of tokenism related to family participation.*** Both family members and providers indicated that verbal or written commitment to family participation in systems of care never guarantees that participation or collaboration will occur. It is possible for providers to indicate support for family participation and family-provider collaboration, and to not value participation or practice collaboration. The language, philosophy, and expectations (at local, state, and federal levels) addressing family-provider collaboration are often vague. Lack of structures of accountability also make it likely that tokenism exists.





## Appendix B

### LIST OF ACRONYMS AND ABBREVIATIONS

C&A	Child and Adolescent
CAN	Child and Adolescent Network
CASSP	Child and Adolescent Service System Program
CATCH	Citizens Acting Together Can Help
CCO	Creative Community Options
CFAC	Children and Families Advocacy Corporation
CHADD	Children and Adults with Attention Deficit Hyperactivity Disorders
CMHI	Child Mental Health Initiative
CMHS	Center for Mental Health Services
ESPDT	Early Periodic Screening, Diagnosis and Treatment
<i>FACES</i>	Families and Communities Equal Success
FACT	Families, Agencies and Communities Together
FIT	Families Involved Together
FPT	Family Partnership Team
FRCU	Family Resource Coordination Unit
F.R.I.E.N.D.S.	Families Reaching in Ever New Directions
I-CAN	Individuals in Community Advocacy and Networking
MHA	Mental Health Association
MH/DD/SAS	Mental Health, Developmental Disabilities and Substance Abuse Services Programs
NAMI	National Alliance for the Mentally Ill
NC-AMI	North Carolina Alliance for the Mentally Ill
PEN	Parent Education Network
<i>PEN-PAL</i>	Pitt-Edgecombe-Nash Public Academic Liaison
PIN	Parents Involved Network
PYAP	Philadelphia Youth Advocate Program
QIT	Quality Improvement Team
ROC	Raising Others' Children
SCFC	Stark County Family Council
SPFP	South Philadelphia Family Partnership
T.E.A.M.S. (Parent)	Training, education, advocacy, mediation, and support
<i>WE CARE</i>	With Every Child And Adult Reaching Excellence
WCCMHC	Waianae Coast Community Mental Health Center
WNC	Western North Carolina





